

## Access to healthcare information and comprehensive care: perceptions of users of a public service

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The aim of this study was to identify the perceptions of patients at a healthcare service regarding the right to information and comprehensive care. This was a qualitative, exploratory investigation with an analytical-descriptive orientation, for which the theoretical axis was the right to health-related information access and comprehensive care. The following categories were constructed: difficulties in achieving humanized healthcare in a primary unit; depersonalization of professional/patient relationships; gaps in physical and human infrastructure of the service; and interpersonal relationships among the different players in the care process. Access to information constitutes a central aspect of promotion of comprehensive healthcare. To be able to provide this adequately, it is important to make professionals aware of the importance of user empowerment, so as to make users the protagonists of care and have them as allies in the care process.

*Keywords:* Right to health. Access to information. Comprehensive healthcare. Humanization of care. Public Health.

## Introduction

Health began to interest the area of Law initially with the notion that there is something called “public and collective health” that needs to be protected. Thus, hygienism was accompanied by the first legal norms, which aimed to intervene actively towards the protection of public and collective health – the former understood as being related to governmental actions, while the latter views the subjects in their totality – as biopsychosocial subjects<sup>1,2</sup>. However, only with the international political reorganization in the mid-20<sup>th</sup> century and the creation of the World Health Organization (WHO), in 1946, did health begin to be recognized as a human right; it started to be legally protected in the modern States by means of norms that establish obligations to the government and to the citizens for its fulfillment.

In Brazil, the right to health was affirmed with the 1988 Constitution of the Republic, which recognized it expressly as a fundamental right of the human being and established the guidelines to the operationalization of healthcare in the country: decentralization, comprehensive care and community participation<sup>1</sup>.

Based on those guidelines, Law 8080/90 was created. It instituted *Sistema Único de Saúde* (SUS – Brazil’s National Healthcare System) and established in its article 7, item II, the principle of the provision of comprehensive care, understood as “an articulated and continuous set of preventive and curative, individual and collective actions and services required to each case in all the levels of complexity of the system”<sup>1</sup> (p. 223).

However, the provision of comprehensive care is not only a basic guideline of the SUS. More than this, it proposes the development and expansion of the care provided by health professionals<sup>3</sup>. Comprehensive care “can be perceived as a set of notions pertaining to an amplified assistance, with articulation of the professionals’ actions, in a comprehensive view of the human being, who has feelings, desires, afflictions and rationality”<sup>3</sup> (p. 134).

Therefore, comprehensive care needs to be dealt with in several dimensions in order to be achieved, and it can be subdivided into focused or amplified. Focused comprehensive care would be related to the commitment and concern of the healthcare team at a certain service to perform the best possible hearing of the health needs brought by the individuals who look for assistance. It encompasses good living conditions and capacity for access to and consumption of health technologies that are able to improve and prolong life, and it is achieved by means of affective and effective bonds between user and team/professional, which establish a trust relationship. Amplified comprehensive care, in turn, is thought of in terms of networks; thus, it corresponds to the articulation between the healthcare services and other institutions, as the technologies are distributed across different services and the improvement in the living conditions depends on an intersectoral articulation<sup>4</sup>. This study approaches focused comprehensive care, which is the point of departure that will enable to discuss health information as a means to achieve comprehensive care.

## **Fundamental right to health information**

Article 5, item XIV of the 1988 Brazilian Constitution ensures the right of access to information for everyone, protecting the confidentiality of the source whenever necessary to professional exercise.

As every person's access to information is considered an individual right, the fundamental right to health information is highlighted here, that is, the right that the users of a public health service have of being informed of all the aspects that involve their health, and the services guarantee the access to information by right.

However, only something that is understood can be called "information", that is, when there is, on the part of the cognizing subject, consensus regarding its meaning<sup>5</sup>. Otherwise, it is not information. Another aspect that is worth discussing here refers to the qualities, relevance and purpose that are inherent in the term "information", as the cognizing subject searches for information with a certain objective, either consciously or unconsciously; however, human mediation is necessary, as what is information for someone may not be information for someone else.

Therefore, when the information is mediated by the health professional, it needs to be adapted to the person, as the information transmitted to an individual may not be understood by another individual in the same way. Thus, the user or cognizing subject re-signifies the information, synthesizes it and contextualizes it in his experience.

The discussion about each situation should be adapted to each person's values and psychological/social expectations, without being limited to standardized formulae. Therefore, users must be considered unique, non-standardizable, and the transmission of adequate information must be based not only on the choice of the best scientific alternative, but also on the best alternative to that person<sup>6</sup>.

In this context, the importance of the health professional's mediation is highlighted here. The professional must always adopt a subjective standard to each user, so that the user has cognitive access to the mediated information.

## **Mediation and the empowerment of information by the patient**

Information mediation can be understood as

every action of interference performed by the professional that is direct or indirect, conscious or unconscious, singular or plural, individual or collective, and which enables the appropriation of information that meets, fully or partially, an informational need.<sup>7</sup> (p. 92)

Thus, without the information that is due to them by right, the users are not able to claim and/or fight for their rights; they have neither conditions nor arguments to question, and this hinders the exercise of their autonomy and citizenship.

Citizens are individuals who, in a society, have not only civil and political rights, but also social rights, such as work, education, housing, health and social security benefits. A citizen can only be required to assume responsibilities when the political community clearly demonstrates that recognizes him as its member, through the guarantee of his basic social rights<sup>8</sup>.

Based on this hypothesis, the users' exercise of citizenship is directly related to their empowerment. Empowerment is understood here as the process through which those who have power – in this case, the health professionals – enable the others (users) to acquire and use the necessary power (*information empowerment*) to make decisions that affect them or their lives. Power must not be considered only in the highest levels, but as something that can be shared by all<sup>9</sup>.

The individual's empowerment by means of information has a fundamental role in the person's self-transformation process, as it provides an environment of changes with the aim of offering some autonomy to the individuals involved. Supplying subsidies for emancipation and empowerment is one of the axes to achieve comprehensive care<sup>10</sup>.

In this scenario, information mediation allows the user to move from the category of mere receptor to that of central actor of the appropriation process, that is, the empowerment of information by the user moves him from the category of passive receptor of information to an active and participative being; therefore, a citizen<sup>7</sup>.

The user is the one who determines the existence or not of the information. The information exists only in the interval between the person's contact with the support and the appropriation of the information. As a premise, information is understood based on modification, change, reorganization, restructuring; in short, on knowledge transformation. Understood in this way, information does not exist in advance, only in the relation between the person and the content present in the informational supports. These are concrete, but they need the background, the collection of experiences and the knowledge of each person. Ultimately, the one who determines the existence of information is the user, the person who uses the contents of the informational supports. When information is considered in this way, the active and decisive participation of the user in the process becomes clear. From a receptor, the user becomes a constructor, a co-producer of the information.<sup>7</sup> (p. 96-7)

This transformation of information into knowledge is performed in the individual scope. However, the person, the individual, is not empty, that is, there are no empty spaces in which the knowledge that results from the appropriation of information settles. The person has previous

knowledge, tacit knowledge, and he constructs it in the relation with the others and with the world. In this perspective, information alters previous knowledge and interferes in the construction of new knowledge. This is based on the influence that the individual suffers in the world: social, political, economic or cultural influences<sup>7</sup>.

Health information is included in this context, that is, the act of informing the user about his health or illness and about all the aspects that constitute it. Health information is seen as *process* that enables the appropriation of the information by the user. The mediator, who can be the doctor, the nurse or any health professional, becomes an essential element in the appropriation of information, as he is the one who acts as an intermediary in the communication.

Information, specifically data related to diagnoses, prognoses, test results, explanations about prescriptions, drugs, drug interactions, among others, is analyzed as informed "thing". This enables the user of the healthcare service to know about his rights regarding the service as a potential provider of comprehensive care. When health information is transformed into knowledge, it can lead the patient to appropriate the information. This empowers him and brings possibilities so that he can exercise his right to health effectively.

In view of what has been presented so far, this study aims to identify the perception/opinion of users of a primary care service concerning the right to health information and its potential as provider of comprehensive care.

## **Material and Method**

This is a qualitative and exploratory research with an analytical-descriptive orientation. Its theoretical axis is the right to health, in this case related to access to information and to comprehensive care.

The city that was studied has a healthcare network composed of 26 Primary Care Units, 14 Family Health Units, 5 District Primary Care Units, 1 STD/AIDS Reference Center, 1 Mental Health Nucleus, 1 Alcohol and Drugs Psychosocial Care Center, 1 Psychosocial Care Center for adults, 1 for children, 1 Day-Hospital for psychiatric assistance, and 1 Dental Specialty Center<sup>11</sup>.

This study was developed at one District Primary Care Unit which offers 24-hour emergency services for children and adults, as well as primary care in the following modalities: Medical Clinic, Pediatrics, Gynecology and Obstetrics, Dentistry, Nursing, Home Care, Neonatal Screening and Vaccination.

Twenty-two users of this service participated in the study. They were assisted in medical consultations that had been previously scheduled by the sector of Medical Clinic, and were selected according to the following inclusion criteria: individuals aged 18 years or older who were capable of communicating verbally and of consenting to participate in the study (by signing or pressing their fingertips on a consent document).

The technique that was used for data collection was the semi-structured interview, guided by a script and digitally recorded, based on the following guiding question: "How do you feel when you receive information on your health status, your treatment, and your possibilities of choice related to this treatment?". The interview was conducted in a reserved place right after the medical consultation, in an attempt to collect data during the user's reflective act regarding the moment he had recently experienced.

As for the analysis of the collected data, the interviews were transcribed and analyzed by means of the Content Analysis technique – Thematic Modality. According to Bardin<sup>12</sup> (p. 107), "the theme is the unit of signification that frees itself naturally from a text analyzed according to criteria related to the theory that guides the reading". Thus, the categories were constructed according to the themes that emerged from the process of reading and analyzing the text.

The exploration of the material was composed of three phases<sup>12</sup>: (i) pre-analysis, in which the data were transcribed and organized; (ii) exploration of the material, in which the data were organized by thematic categories and subcategories, revised repeatedly and coded continually. For the coding, the content of the interviews was thoroughly and repeatedly read, as well as the fragments that represented meanings to fulfill the study's objectives; (iii) treatment and interpretation of the results, which were analyzed with the aid of the literature about the object of study, and also of the observation data, culminating in the final remarks.

The research project was submitted to the Ethics in Research Committee of the School of Nursing of Ribeirão Preto (*Universidade de São Paulo*), and it was approved on December 21, 2009 (Protocol no. 1114/2009). Therefore, this study complies with the scientific rigor and the ethical precepts required by the National Ethics in Research Committee (CONEP) for Research conducted with Human Beings, and it ensures the privacy, the anonymity, and the volunteer participation of respondents and the scientific utilization of the results.

## **Results and discussion**

After the thorough reading of the content of the answers given by the interviewees and of the fragments that had potential for contributing and fulfilling the objectives of the study, the following thematic categories were formulated: "Difficulties in achieving humanized healthcare at a primary unit"; "Depersonalization of the professional/patient relationship"; "Gaps in the physical and human infrastructure of the service and interpersonal relationship among the different actors of the care process". They are detailed and discussed below.

### **Difficulties in achieving humanized healthcare at a primary unit**

The research participants emphasized the importance of receiving humanized care during the assistance, which can be seen in the fragment below:

“When we are well diagnosed, when we know exactly what we have, we feel reassured: now I have this and I’m going to treat it. But when we receive disparate information – I’m still feeling this symptom and he says I don’t have anything – we wonder, ‘Why doesn’t he try to investigate more’, you know? But sometimes, knowing exactly what you have depends on the doctor. Some doctors say, ‘you have this’; they explain in detail what we have and we feel relieved. Other doctors say: ‘you don’t have anything’, or ‘you have just a little problem’. This depends on the doctor, on the conscience of each doctor”. (E11)

The situations of fragility of care shown by means of the fragment above are strengthened in the one below, which approaches the importance of the multiprofessional team for the provision, quality and effectiveness of the comprehensive care that is offered:

“If they treated us better... I’d feel more confident about the possible treatments [...] the possibilities that exist and so on; I’d trust the procedure more”. (E20)

The trust reported by the patients is constituted by the therapeutic bond that is established between professional and user in situations in which the professional has attitudes that provide safety and trust. The bond is present since the first moments of the contact. The professional must pay attention to the user, hear what he says, understand his actions, and explain to him his health status and what will be done. Moreover, he must be receptive, approach the patient in a respectful way and show sympathy for his suffering<sup>13</sup>. In addition, the professional must identify himself in a formal way and display the same attitudes towards the patient’s relatives and/or companions.

In other cases, exemplified by the fragment below, it is possible to notice a behavior that, sometimes, is less polite, marked by some indifference, without the attention and the respect to which the user is entitled<sup>14</sup>.

“Well, no, I don’t feel supported because you ask a question and they barely answer it, they talk to you with indifference [...] I feel very bad because I think they should be more humane. I also work in the health area and I think they should be more humane and not treat patients as if they were like any person. If the person is a patient, he should be well treated”. (E9)

Therefore, as user (E9) states, the professionals should be more humane. The current healthcare policies have been increasingly focusing on humanized assistance, which favors the interaction between health professionals and users so that comprehensive care is guaranteed. However, there are many obstacles that can hamper the act of providing humanized healthcare. In many cases, the imperceptible is no longer perceived: seeing the patient in his totality, a being that has emotions, fears and anxieties that, many times, are not spoken, but can be perceived by means of subtle gestures and glances<sup>13</sup>.

On the other hand, the action of providing comprehensive care considering the patient's humanity requires that users have a more autonomous posture as a way of guaranteeing their rights. Nevertheless, so that people can take good care of themselves, they need to be informed, in order to be able to fight for what they want and believe in<sup>14</sup>.

Therefore, so that the users' rights are effectively respected, the assistance provided by the healthcare team needs to be humanized, as the patient is not just a disease; rather, he is a being who has feelings that must be respected and taken into account. Thus, humanization is a *sine qua non* for the provision of comprehensive care in the search for the understanding of the human being's broadest needs. In addition, the articulation between the activities of prevention and assistance must be valued<sup>15</sup>.

Comprehensive care, therefore, goes beyond the visualization of assistance in all the levels of care. It encompasses humanized care and welcoming the patient adequately, considering his environment and individual characteristics<sup>16</sup>. In this sense, the unsatisfactory use of information by the actors involved in the process of care and, therefore, in the process of health communication will certainly hinder the offer of humanized and comprehensive care.

### **Depersonalization of the professional/patient relationship**

The legislation in force has introduced important prerogatives, namely the principles established in the Charter of Healthcare Users' Rights, in 2006, and the State Law 10.241/1999, which guarantees that the patient has the right to be identified by name and surname, and every user identification document must have a space in which the name by which the patient prefers to be called is registered, independently of the civil registry. Therefore, the patient cannot be called by a number, the name of the disease, codes, nor in a generic, disrespectful or prejudiced way<sup>8</sup>.

In this context, it is observed that the professionals need to ask the person's name and how they like to be called<sup>17</sup>. The relationship must respect the reference given by the patient himself.

However, as it has been broadly admitted and disseminated, one of the main factors that influence the questioning of the quality of the healthcare services is the depersonalization of the relationship between the health professional and the patient, which has originated from the so-called "massification" of medicine and of the healthcare services in general<sup>18</sup>.

The patient has always been in a position of subordination and, not infrequently, he is seen as a "case". The pathology he presents is discussed as if it were the "subject" and the patient, a mere receptor of the subject<sup>19</sup>, a reality that is depicted in the fragment below:

"[...] you feel that you're nothing. It's what we are here, a number, a file, that's the way it is. They don't inform you of anything [...]". (E12)

Unfortunately, in many moments, the healthcare team, during the provision of care, forgets that these people have an identity and that they experience their problems as subjects included in a certain reality; therefore, they need to have their rights preserved. These professionals are so involved with the disease, the technological resources and technical sophistications that, in many situations, they do not prioritize the human aspect<sup>20</sup>.

The testimony below shows the depersonalization in the relationship between health professionals and users:

“Well, no, I don’t feel supported because you ask a question and they barely answer it, they talk to you with indifference, right?”. (E9)

The healthcare service user wants to be treated like a biopsychosocial set. However, he realizes that, when he arrives at the unit, he is no longer a person, as he receives a treatment that considers neither his identity, nor his history of life; thus, he becomes a hospital bed or a disease that needs to be treated<sup>20</sup>.

The difficulties resulting from the depersonalization of the interaction with users negatively affect the provision of comprehensive care and the exercise of any right, as the patient participates in this relationship as an object, and not as a participant and the subject of his own history. This reveals that depersonalization is a daily practice that runs contrary to the actions of the Ministry of Health targeted at the humanization of care<sup>21</sup>.

### **Gaps in the physical and human infrastructure of the service and the interpersonal relationship among the different actors of the care process**

Another aspect that is worth highlighting here is the very short duration of the medical consultations, which result in the promotion of a cold and inhumane environment, rather than one that is receptive and attentive to the user’s needs. The users report that the doctors do not examine them; they only prescribe medicines without previously assessing their health status:

“So much so that she [the doctor] didn’t even put her hands on me, she just spoke to me, she was over there and I was over here... Because, first of all, if I go there [in the doctor’s office] and say that I have a stomachache, she gives me the medicine for stomachache. She’ll just hear what I’m saying, you see? She won’t examine me to know what I have and she won’t ask for any tests, you see?”. (E1)

We know that the user has the right to receive assistance with the best possible quality,

“founded on a solid basis of knowledge and provided by people who can employ these bases of knowledge, applying adequate judgments and reasoning and a clear and convenient system of values”<sup>22</sup> (p. 451-2).

However, situations embedded in the professionals’ daily routine may affect the performance of their functions. When tiredness emerges, together with the will to conclude the medical consultation and the pressure created by other users in the waiting room, the professional may be led to meet some demand that is more urgent and does not give proper attention to the patient/companion, as it can be seen in the fragment below:

“Sometimes I get angry. When you arrive there you’re in pain, you’re feeling something. They perform the tests, sometimes the doctor doesn’t even listen to what you’re saying, you’re telling him what you feel and he’s already finishing the prescription, sometimes he doesn’t examine you, sometimes he doesn’t even touch you, he looks at you as if he were a medium, looking at you and writing, so there isn’t much space for you to say what you’re really feeling, and we realize that what he wants is that you enter into his office, he writes the prescription and you go away immediately. I think he doesn’t want to find out what you have; he wants to liberate the space so that the next patient can come and so on”. (E13)

Those who propose to assist the human being must assume a posture of respect and commitment, valuing the life experience of the users of the service at which they work, enabling them to preserve their individuality, as each person needs one type of care<sup>20</sup>. Hence, it is dangerous to focus only on the disease, as the same illness may present different manifestations in distinct people.

Therefore, comprehensive care is guaranteed only when actions like available hours at the healthcare unit and effective communication with the staff are offered to the user<sup>16</sup>, which corroborates the understanding that the exercise of the right to information must be valued so that more effective communication is achieved among the diverse actors of the care process.

## **Conclusion**

The right to health is fulfilled with its constitutionalization as a social right in Brazil’s legislation. With the promulgation of the 1988 Brazilian Constitution, health started to be treated as a citizen’s right and its guarantee was established as a duty of the State. The institutionalization of the SUS in 1990, which has advertised universal, equitable and comprehensive assistance, was in accordance with the constitutionalization of such right. In this study, it was possible to observe the

difficulties faced by the users of a primary care unit in relation to access to health information, which is related to the provision of comprehensive care.

The right to health information is a right that is legitimated by the information mediated by the health professional. Such information enables the patient to empower himself, generating knowledge; consequently, it allows him to exercise his citizenship.

Concerning the right to information, the legislation in force establishes that the user has the right to receive clear, objective and understandable information on his health status. This study allowed to identify information as a key point for the promotion of comprehensive care, by means of humanized health actions targeted at the establishment of a clear communication process.

Therefore, one obstacle to the promotion of comprehensive care is the lack of access to true information on the user's health, which was pointed as a difficulty by the users, as they would like to receive true and high-quality information. The interviewees emphasized that truth, respect for and empathy with the other can strengthen and humanize the relationship between the health professional and the user. Another obstacle that was mentioned in the study are the difficulties in the interpersonal relationship with the user, especially due to the short duration of the medical consultations. When the professional assists many users in a short period of time, he does not provide assistance with the expected quality; many times, he treats them as a number, a file, a disease. In some cases, the professional prescribes medicines based only on what the user says, without examining him and without listening to his complaints – we emphasize here the depersonalization of the patient.

In addition to the difficulties reported here, the excess of bureaucracy in the system is a problem that emerged in the study, as it hinders the functioning and the provision of comprehensive care advertised by the SUS. In this perspective, it was observed that the problem is not the existence of formalization, which is necessary in organizations of such large dimensions; rather, it is the excess of rules that, instead of facilitating the working process, many times hamper the effectiveness of the service provided for the user of the healthcare system.

In short, it is possible to state that the exercise of the right to health information is a pre-condition to reduce the user's vulnerability and to promote his empowerment, enabling him to exercise different possibilities of choice related to his own health, so that he has the conditions to become one of the subjects of the health professional/user relationship.

To promote the balance among the powers of those involved in this process, it is fundamental that the health professionals recognize the patient as a user; in fact, as a human being who has a distinct life history, feelings and needs, and not only as "one more" patient to be assisted among many numbers and diseases. For this to happen and so that comprehensive and humanized care is provided, the professional must use a subjective standard in his communication with the user, playing the role of mediator in this relationship. In this perspective, the health professional must put himself in the user's shoes, understanding his particularities.

However, although the principles that rule the SUS model recommend the provision of comprehensive and humanized care, in fact, the system represents a model under construction that faces challenges in its operational and human resources management. The overload of assistances, the scarcity of human support and physical resources, as well as the excess of formalization, constitute, in this context, serious obstacles to the transformation of the patient into user in the relationship with the health professional and through the exercise of his right to health information.

Despite the existing gaps and challenges, the study revealed signs and possibilities of change towards the joint construction of more democratic relationships in which the user, as a subject, exercises rights, but also is conscious of his obligations as a citizen, especially regarding his relationship with the professional and the healthcare service.

One limitation of the research is the impossibility of generalizing the data, as the study was carried out at one District Primary Care Unit in the city of Ribeirão Preto. In this sense, we suggest the development of investigations that approach the exercise of the right to health information in other healthcare services and in other regions of Brazil. Another suggestion is that public policies should be made to educate the population and to explain its right to information, and also to educate the mediators of such information, with the aim of enabling them to have access to the information about their rights as users of the public healthcare service. Thus, access is configured as a pre-condition to the user's empowerment, offering him the possibility of becoming a real user, conscious of his rights and duties related to his own health.

### **Collaborators**

Renata Antunes Figueiredo Leite conceived and designed the research, analyzed and interpreted the data, and wrote the paper. Emanuele Seicenti de Brito collected, transcribed and interpreted the data, and wrote and revised the paper. Laís Mara Caetano da Silva wrote and revised the paper.

Pedro Fredemir Palha reviewed the paper critically. Carla Aparecida Arena Ventura conceived, designed and reviewed the paper critically.

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