Privacy and confidentiality of users in a general hospital

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Abstract

The privacy and confidentiality of users are often disrespected within the hospital setting. The present study, consisting of an exploratory and qualitative survey, was performed in a general hospital located in Pau dos Ferros, in the state of Rio Grande do Norte, Brazil and aimed to analyze the perception of users regarding aspects related to their privacy and confidentiality during hospitalization The semi-structured interview technique with content analysis was used for data collection. After data analysis, two categories were created: the privacy of hospitalized users and the confidentiality of their data. The results showed that interviewees had an ambiguous understanding of privacy and confidentiality and a limited comprehension of these issues. As they were not aware they had such rights, they did not associate invasive situations experienced during hospitalization with disrespect. In addition, the speeches of the participants showed passivity and acceptance towards the care received. It is therefore hoped that the results of this study can contribute to the expansion of discussions about the ethical aspects studied and possible improvements in health care.

Keywords: Patient care. Hospitalization. Privacy. Confidentiality. Ethics, institutional.

Resumo

Privacidade e confidencialidade de usuários em um hospital geral

No ambiente hospitalar, privacidade e confidencialidade dos usuários são frequentemente desrespeitadas. Esta pesquisa, exploratória e qualitativa, realizada em hospital geral localizado em Pau dos Ferros, Rio Grande do Norte, Brasil, objetivou analisar a percepção de usuários sobre aspectos relacionados a sua privacidade e confidencialidade durante a internação. Utilizou-se para a coleta de dados a técnica da entrevista semiestruturada com análise de conteúdo. Após análise dos dados, foram criadas duas categorias: privacidade dos usuários hospitalizados e confidencialidade dos dados dos usuários hospitalizados. Os resultados demonstraram que os entrevistados têm entendimento ambíguo e limitado sobre privacidade e confidencialidade. Por não saberem que têm esses direitos não associaram situações invasivas durante a internação ao desrespeito. Além disso, os participantes manifestaram em suas falas passividade e aceitação diante dos cuidados recebidos. Logo, espera-se que os resultados deste estudo possam estimular discussões sobre os aspectos éticos estudados e aperfeiçoar os cuidados em saúde.

Palavras-chave: Assistência ao paciente. Hospitalização. Privacidade. Confidencialidade. Ética institucional.

Resumen

Privacidad y confidencialidad de los usuarios en un hospital general

En el ambiente hospitalario, la privacidad y la confidencialidad de los usuarios son a menudo irrespetadas. Esta investigación, exploratoria y cualitativa, realizada en un hospital general ubicado en Pau dos Ferros, Rio Grande do Norte, Brasil, tuvo como objetivo analizar la percepción de los usuarios respecto de los aspectos relacionados con su privacidad y confidencialidad durante la internación. Para la recolección de datos se utilizó la técnica de entrevista semiestructurada, con análisis de contenido. Luego del análisis de los datos, se generaron dos categorías: privacidad de los usuarios hospitalizados y confidencialidad de los datos de los usuarios hospitalizados. Los resultados demostraron que los entrevistados tienen un entendimiento ambiguo y limitado sobre privacidad y confidencialidad. Por no comprender que poseen estos derechos, no asociaron situaciones invasivas vivenciadas durante la internación con falta de respeto. Además, los participantes manifestaron en sus discursos pasividad y aceptación ante los cuidados recibidos. Así, se espera que los resultados de este estudio puedan estimular discusiones sobre los aspectos éticos estudiados y perfeccionar los cuidados en salud.

Palabras clave: Atención al paciente. Hospitalización. Privacidad. Confidencialidad. Ética institucional.

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The recent advances in the field of health care require increasingly skilled and competent professionals to deal with the complexity inherent to the individual and collective needs related to the growing demands for care, as well as the aspects related to the defense of their rights. Often the interaction between professionals, staff and users of heath care services generates conflicts that come mostly from differences in values, beliefs and goals of those involved. In this context, mutual respect and awareness about rights and duties are indispensable so that nobody is harmed [1].

This perspective is anchored, among others, in the Universal Declaration of Human Rights [2], promulgated in 1948 by the United Nations (UN), which, in article 12 states that No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honor and reputation. Article 5, paragraph X of the Constitution of the Federative Republic of Brazil also states that the privacy, honor and image of persons are inviolable, ensuring the right to compensation for material or moral damages resulting from their violation [3].

One of these advances in health was the approval by the National Health Council ("Conselho Nacional de Saúde" - CNS) of the Charter of the Rights of Health Users ("Carta dos Direitos dos Usuários da Saúde"), one of the greatest information tools for users, about rights and duties in public or private health care. Article 4, paragraph III provides that *in consultations, diagnostic, preventive, surgical and therapeutic procedures, as well as in hospitalization, the user has the right to privacy and comfort and to confidentiality of all personal information* [4].

Privacy and confidentiality have been the object of studies and reflections throughout history. In their early days, ethical regulations refer to Hippocrates, who would have formulated principles and norms with the aim of defending the rights of patients with regard to information transmitted to health care professionals. One of the precepts refers to the moral duty of the professional, who must keep the secrecy of information about the life and health of the individual under his care. The Hippocratic oath is considered the foundation of the ethics of health professionals [5].

In health care, the privacy and confidentiality of patients can be violated in different ways and at different levels, such as personal and territorial spaces, body, information, psychological and moral fields. However, it is difficult to establish limits between the rights of users and the need for professionals to intervene, since touching the body and obtaining information during care are medical needs, but they can hurt users' rights depending on how such interventions occur [6].

The terms "privacy" and "confidentiality" are directly related to normative values, which rule the practices of health professionals. However, conceptually, privacy and confidentiality differ: the former refers to status or the right to privacy, allowing the user confidence and security to reveal something intimate; the latter must ensure that the information disclosed is kept secret. Confidentiality can still be defined as a type of informational privacy and occurs in health care when information is disclosed to the professional in the context of the clinical relationship, and the clinician, when he becomes aware of it, is committed not to disclose it to third parties without the permission of the informant [7,8].

In this sense, maintaining privacy and confidentiality of the information acquired is configured as an ethical virtue, which is revealed only when someone exercises it on a daily basis. Therefore, it takes the efforts of those involved in the care process in order for the privacy and confidentiality of patients in the hospital environment to be respected [5].

The condition of illness causes negative feelings, such as those of inability, dependence, insecurity and a sense of loss of control. Users view the hospitalization process as a factor of depersonalization because they recognize the difficulty of maintaining their identity and privacy. For the patients, therefore, the hospital environment becomes stressful especially because it loses control over what affects them, over their own bodies and for not controlling those on which their survival depends. In addition, due to emotional and physical exposure, the hospitalization is distressing because it emphasizes the fragility they are subjected to [9]:

The patient presents his complaints, tells his story and offers his body as a stage. From then on, he becomes an audience, waiting eagerly for the unfolding of a plot of which he no longer participates actively and autonomously [5].

Due to the increase of conflicts that generate vulnerability to users of health care services, ethics commissions have been created in hospitals in order to analyze, interpret and adapt the activities of professionals according to ethical values, rights, duties and the legislation of each professional category [9].

In view of the above, this study aimed to analyze the perception of patients regarding aspects related to their privacy and to the confidentiality of

their data during hospitalization. In this perspective, this study results in possibilities of reflection and resources for professional practices, both of the institution researched and others. Thus, this study should contribute to a more human and ethical health care that respects the rights of its users.

Methods

This is an exploratory research, with a qualitative approach, performed at the Dr. Cleodon Carlos de Andrade Hospital ("Hospital Dr. Cleodon Carlos de Andrade" - HCCA), a general hospital located in the city of Pau dos Ferros, Rio Grande do Norte, Brazil. The municipality has 27,745 inhabitants, occupies a territorial area of 259,959 km², with a population density of 106.73 people per km² and is located 410 km from Natal, the state capital [10].

The study participants were the patients hospitalized in the medical clinic, surgical clinic and Adult ICU, selected by the following criteria: age equal or above 18 years; length of stay longer than 24 hours; and who demonstrated cognitive (conscious and oriented) conditions to understand and answer the questions of the instrument of data collection.

As an instrument, the semi-structured interview was used by means of a script adapted from a nursing thesis [1] and conducted individually with each user in his/her bed. The original script was adapted because it only deals with privacy and refers only to the nursing category, and this research also explored confidentiality issues and involved all health staff. The application of the interview was performed by the authors of this study.

Data collection was performed between june and august, 2015 and concluded according to the technique of saturation of qualitative data, that is, when the data became repetitive. Finally, respecting the voluntary nature to participate in the study and through the criteria of selection and saturation criteria, 34 users were interviewed.

The data were examined through the content analysis proposed by Bardin [10]. This technique is organized in three phases: pre-analysis, material exploration and treatment of results, and inference and interpretation. After exhaustive reading, the statements were organized and classified into two themes: "privacy of hospitalized users" and "confidentiality of hospitalized users". In order to preserve the identity of the interviewees, the identification with the letter "U", from the term "user", followed by Arabic numerals representing the order of interviews, was used throughout the text.

Results

Characterization of the subjects

The study had the participation of 34 hospitalized users. Of these, 17 (50%) were from the medical clinic sector, 14 patients (41%) were from the surgical clinic sector and three (9%) had their interviews performed in the adult ICU sector. The average time of hospitalization was 3 days, calculated from the participants' individual hospitalization data, with the minimum time being one day and the maximum of 16 days. The mean age was 49 years, with a minimum age of 20 years and a maximum of 76 years.

The majority of respondents, 18 (53%), were male; 18 (53%) came from the rural area; 19 (56%) declared themselves as brown; 14 (41%) were farmers; 30 (88%) were Catholic; 15 (44%) were married; 18 (53%) had incomplete primary education; and 17 (50%) had family income corresponding to a minimum wage at the time of data collection.

Privacy of hospitalized users

This thematic category portrays the interviewees' understanding of the term "privacy", covering specific issues such as: authorization request in certain situations by health professionals; feelings or sensations of the participants about the bath in the hospital; and situations in which participants would have felt disrespected.

The answers to the interview revealed ambiguity regarding their understanding of the term. Some denoted limited understanding about the issue, while others showed little or no knowledge, as discussed in the following statements:

"Privacy is having your own place, a place for yourself. It is having your privacy so that you can do your things yourself. Without interference from other people and without also taking the place of other people." (U4);

"Privacy is to have our privacy. No one invades our privacy. It would be my space, my own little place." (U5);

"*It would be like, if I had a serious illness and if I did not want to expose it to anyone, this should be respected, in my sickness."* (U24);

"I do not understand anything about this business." (U3);

"I do not understand that. Explain it. " (U21);

"*I do not understand what it is. Is privacy the eprivation of these things?"* (U28).

Participants reported that health professionals asked for permission when they needed to expose some part of their bodies. Regarding this, the answers showed that the interviewees were divided about their preference for being alone with with professionals who performed the care:

"They ask [for permission]. *No, I don't mind"* (U5);

"They ask [for permission]. *I don't see a problem. Such a natural thing. We are here, in the hospital, in need of care"* (U17);

"*Yes, certainly. They ask for permission. I don't think so. No problem. Because it will be for my health. It will not cause embarrassment for me"* (U24).

In the following answers the respondents showed a preference for being alone in situations of exposure. Women, in particular, commented that they preferred to be alone mainly in relation to the presence of men, as the following statements illustrate:

"(...) *being alone, we feel more at ease"* (U7);

"*I would be embarrassed, especially if it was a man. I prefer to be alone. And I am, too old, embarrassed."* (U21);

"*I do not feel uncomfortable.* [Even if it is a man?] *No. if it is a man, we* [laughs]. *Because men, we really do not accept, because we are not at ease. We want to change clothes, we want to be ate ease. If here are only women here, we are at ease. And, furthermore, we do not accept men here, not even as companions, because this ward is for women only. We do not accept it"* (U28).

In contrast to the previous reports, others reported that the professionals did not ask for authorization or that they did not consider it necessary, since the users themselves or their companions took pieces of clothing off the patient, partially or totally, for example, for specific actions of the professionals. The following statements reveal this understanding:

"*No, sometimes, also, it is something for a dressing, then I take it off myself. Before they start, I take it off"* (U23);

"*No, they do not ask.* (...) *She does it, she* [companion] *takes it off me"* (U28);

"*No, because only a* [male] *physician came here today. No, he did not ask for permission, I got up like this and showed it to him. He did not ask for anything."* (U29).

The interviews showed that users who needed help in the bath, whether in the infirmary bed or in the bathroom, revealed feelings such as embarrassment and dependence or a strange feeling during some moments in the hospital stay. These reactions were l when help was familiar:

"Now, *she* [companion] *is the one who bathes me. She gives me a bath in the bathroom. I have stayed in the chair, I get up. When she is going to wash my hair, I lean back in that chair. We feel* [pause] *we are not nobody in this life, don't we'? Why, for God's sake, I feel so much depend*[ent] *of others. It is the greatest sadness."* (U5);

"(...) *they* [companions] *bathe us here on the bed. I have a broken leg and can not stand up.* [how do you feel?] *They're my daughters, I feel good, even."* (U7);

"*Yes. The bath is on the bed. They smear water. I am frightened, I am very ashamed, I feel like not myself. In that moment, I think they are washing someone else, so ashamed I am. I am used to taking a bath alone"* (U16).

General responses were sought from patients about possible disrespect for their privacy in the hospital environment. Respondents stated that they did not identify a situation that represented disrespect, as expressed in the following statements: "*No. At no time"* (U1); "*No. Thank God I am* [being respected]*"* (U11).

Among the answers, there are those who have understood their privacy was respected because of the good quality of the care; some complained about specific privacy issues; and others stated that it was not possible to have privacy in a collective hospital environment and therefore had to accept the situations experienced. The following statements exemplify these views:

"*No. I do not think it's disrespectful. Now, I believe that in the face of the situation that we are in, or even when you are sick in a hospital, you can not have privacy just for you.* (...) *Sharing the bathroom with other people, the bed you are in, accepting visits. And to understand that we are not in our house and it is a space that belongs to everyone"* (U4);

"*I'm being well cared for, thank God. I do not feel disrespected at any moment. If I did, I would speak out."* (U24);

"*Illness is a serious issue. Then because of the illness you have to go through these situations"* (U31).

Confidentiality of hospitalized user data

Highlighted in this thematic category are: the interviewed users' understanding of the term "confidentiality"; issues of secrecy of information in cases where professionals may disclose data about users to third parties; authorization request from the professionals to pass information about the users to their teammates; and situations that may have caused disrespect to the participants regarding aspects of confidentiality during hospitalization.

As with privacy, the responses obtained revealed ambiguity regarding their understanding of the term "confidentiality." The answers showed that the users associated the term with something secret, intimate, personal and that should not be spread to everyone; they also related the term to something inherent to the practice of professionals. The interviewees mentioned the issue of the right to have information about their state of health. In addition, some responses demonstrated limitation or lack of knowledge about the concept. The following statements illustrate these findings:

"*Secret. Intimate. Personal. Something secret and intimate that is yours"* (U4);

"*There are many things that it is better to keep to oneself. There is no need for everyone to get* [to know]*... to spread..."* (U12);

"*Only you, the doctor and your companion. That is it. Only these three have to know this information"* (U17);

"*It's a secret. Something like that, from a friend. It's confidential. That you do not have to tell anyone"* (U29);

"*I think one should have some information, know what one has, what one needs. I think I needed that. But then, sometimes we are left loose,* (...) *I have a right to know, one is either okay or bad. I wanted to know that*" (U13);

"*Boy, I do not know what ''confidential'' means. I'm sorry. I'm from the countryside, very illiterate, I do not know."* (U7).

Those interviewed in this study did not hear health professionals talking about them or about other users to third parties during hospitalization and stressed that, if such situation occurred, it would be a reprehensible and unethical attitude, this was evidenced in the following statements:

"*No. Not at any moment.* [What do you think about this?] *I would think he* [professional] *is not ethical. He would be unfit for his profession, he would have to look for another profession."* (U4);

"*No.* [In case it had happened?] *I think it would be wrong. A doctor in medicine consults with her* [other use] *and goes around telling people. I think it is wrong"* (U7);

"*No.* [In case it had happened, what do you think?] *It depends on the situation.* (...) *But, if it was telling, exposing something personal about him, then it is not cool"* (U25).

As for the request for authorization for the transfer of information from professionals to teammates the interviewees revealed that these actions did not occur, that is, the professionals did not request authorization in these situations.

Respondents were dubious in their responses, as they did not comment on the fact that the professionals did not request permission to pass information to the team, relating the questioning merely to the transfer of information by the professionals to work mates. In this sense, the participants considered it correct to pass information, as it is a necessity for the communication of the health team. Among the statements, some considered that the request for authorization is not necessary in these situations:

"*They ask.* [And otherwise, if they didn't?] *No, I find it correct not to. Because, for example, he comes, he already knows. But the others who re not aware of the case, how are they going to be able to follow?*

Then, the right thing to do is to share information with the others" (U17);

"*So far, they haven't asked.* [What do you think?] *Being a professional, they can share, no problem. I think not."* (U19);

"*No.* [What do you think about this?] *I don't even know how to answer. I think with work mates, he can share, I think it's normal. I don't see the need* [to ask permission to share information]*, he can see my situation and all, he is going to talk to his colleagues, I think so"* (U23).

It is evident in the interviews that the users did not feel disrespected during the hospitalization in relation to aspects that involve confidentiality. Among the responses, users reported occasional situations in which they felt disrespected, but that were not necessarily associated with confidentiality, according to the statements extracted from the interviews: "*here they are very fine people. Good people. I have nothing to say about anyone*" (U1); "*No. I did not feel* [disrespected]" (U10); "*No. I have not seen, so far I have not seen and I hope I do not see. Because it is very good here, we are very well respected, very well received*" (U34); "*No. There is not. Just the situation of the old lady. But it was necessary, she was going senile, screaming. She spent the night screaming*" (U3).

We understand that users who did not interpret information exchange among professionals as a breach of confidentiality may not be wrong when considering the exclusively pragmatic aspect of the issue: the perspective by which they "learn" about the reality of the hospital. Even with training efforts, the eventual exchange of information (which should remain confidential) still tends to occur in the daily life of large institutions. Considering this process, it may be possible to better understand the interpretation of users about confidentiality, since their knowledge is probably derived from the observation of the dynamics to which they are effectively subjected during hospitalization and not from formal education about the rights and duties of the user in hospitals.

From another perspective, users have shown relief for being hospitalized for treatment because they felt welcomed and viewed these aspects as manifestations of "respect", believing these aspects to be more important in relation to what led them to hospitalization. Respondents also showed recognition of the professionals' knowledge and respect, crediting them with decision-making power over treatment. That is, the participants indicated that, although they do not know enough about their rights to privacy and confidentiality, they recognize the quality of the health service with regard to the reception and treatment offered.

In this context, it is understood that the insufficiency of knowledge about what is confidentiality and its aspects may have influenced the responses of the participants, who reported not having noticed or experienced situations of disrespect in the hospital environment. It was concluded that, due to lack of knowledge about fundamental rights of citizenship and health, many users were unable to go deeper in the discussions.

Discussion

The testimonies highlighted issues involving both privacy and confidentiality. The interviewees of this study presented an ambiguous understanding about such terms, which indicates insufficient knowledge, indicating that, although they claim to receive good treatment during hospitalization, their health education is lacking because they do not know important aspects of their rights: *The right to information in health is legitimized from the information mediated by the health professional, allowing the users to empower themselves with this information, generating knowledge and enabling them to exercise their citizenship* [12].

Regarding the understanding of the term "privacy" by the users, a study by Pupulim and Sawada [13] found that the view of hospitalized users associates privacy with dignity, respect, personal and territorial spaces, and autonomy. In general, these concepts are really integrated and indispensable to the protection and maintenance of one's privacy not only in the hospital, but also in all other health services. It should be noted that the level of education of the study participants mentioned is higher than that of the users interviewed in this study, which may have influenced the difference of understanding.

In the manifestations of the interviewees in the study by Soares and Dall'agnol [5], negative feelings and reactions of users' indignation were evidenced by the disclosure of data related to their living and health conditions by the staff of the institution, who have the duty to preserve the confidentiality of information. The reaction of the interviewees in the present study was different, and again, this divergence can be attributed to the lack of adequate knowledge

about the meaning and the sense of confidentiality, which probably influenced the fact that they were not reactive regarding the non-preservation of data.

The request for permission to undress and touch the user is an attitude that serves both to value the user as an individual and to recognize one's right to have one's body under one's own domain. The user must be able to determine how, where, when and by whom his/her body will be undressed and touched, this being a way to control the access to oneself, granting protection of one's moral identity and autonomy to decide by and for oneself [14,15]. Professionals generally act in a linear fashion, without restrictions, forgetting to ask for authorization whenever there is a need to touch the user. As they consider this procedure an inherent part of their work routine, they do not understand that this attitude may be violating the privacy and intimacy of the user, and could even be interpreted as an ethical infraction [16].

Regarding the preference for being alone or not during more intimate procedures, a study by Souza and Brandão [17], with patients in surgical units in a medium-sized hospital, found that at the moment of exposing their intimacy, the interviewees preferred to be alone with someone from the professional team or with some trusted member of their family. Such consideration indicates that even in a public place, such as an ICU or ward, patients feel the need to recognize their privacy and the right to intimacy.

Another study by Pupulim [15] with hospitalized users found a similar situation, because, when asking for a place for themselves, to keep away from other patients, the subjects expressed a desire for isolation, preferring not to share the same ward. The discomfort of some users with the presence of others in the same room is clear, since this implies sharing not only space, but also aspects of the personal and intimate sphere, such as conversations with visitors and professionals, even in relation to rest, hygiene and other activities.

In agreement with the findings of the present study regarding the gender of the health professional, two studies identified user preferences by same-sex caregivers [6,18]. Souza and Brandão [17] also interviewed 20 patients hospitalized in medical surgical wards in a medium-sized hospital in a municipality in the state of Goiás, stating that the interviewees reported unpleasant experiences regarding the care performed by a professional of the opposite sex.

Consistent with the results of this research, a study by Nepomuceno et al. [18], carried out in a school hospital in the city of Itajubá, Minas Gerais, Brazil, collected considerations and feelings of 20 hospitalized patients about having a bath in the hospital. The feeling of embarrassment was reported by the interviewees as a result of being naked in front of a professional of the opposite sex as well as of the lack of privacy, a feeling that could be avoided if the care was provided by a professional of the same sex or by the use of a screen. They also said they felt incapable of caring for themselves at the hospital because of the fact that bathing was a basic daily need, usually done without help.

Of the six patients interviewed in the study mentioned above [18] who said they had needed help to bathe, five stated they felt embarrassed. Regarding body exposure, of the 34 interviewees in the present study, 13 reported being embarrassed with the presence of professionals and 21 said they did not feel shame or embarrassment in this situation. Consistent with the results of this study [18], the above mentioned study by Souza and Brandão [17] found that participants expressed feelings of discomfort and embarrassment during the care they received, especially regarding the need to expose the body, whether in the bath, in the change of dressings, in the change of personal clothing, among others.

Another aspect analyzed and also evidenced in previous studies [1,15]: the issue of users relating the fact that they are well cared for and well treated to aspects that guarantee their privacy. Respondents showed little expectation about privacy in the care received at the institution. For them, privacy refers to the experience of health professionals, associating ideas with helpfulness and kindness in treatment.

In agreement with the results of the present study, the study of Pupulim and Sawada [13] found that patients considered it difficult to protect and maintain their privacy in the hospital and seemed to either wait for professionals to take action in this respect or to conform with the situation for being temporary and necessary.

Some patients understood that confidentiality is to have the right to know information about their state of health. In fact, this interpretation represents one meaning of the term. The user of the health service has the right to health information, that is, the right to be informed about all aspects that involve their health. In this context, the unsatisfactory use of information, by the actors involved in the care process, can certainly make it difficult to offer an effective humanized and integral care [12,19].

Regardless of the issue of disclosing confidential information, it should be noted that the duty of confidentiality, such an old precept in the area, is still one of the most disrespected ethical commitments in the health care system. Conversations in corridors about patients' illnesses, patients' records on counters, with information exposed, or even the physical layout of stretchers and beds, unnecessarily exposing the user, are common.

We must also add the fact that even information apparently banal to third parties can be considered very secretive by the patients, in their scale of values. Thus, the rule should be to keep secrecy concerning all information about the patient by avoiding unnecessary comments [20].

It should be noted that information provided by patients during their hospital care is their property. For a long time it was thought that this information belonged to the physician or to the health institution. From this misguided view came the names "medical record" and "medical file". With the new times, the increase of the Unified Health System ("Sistema Único de Saúde" - SUS) and its doctrinal and organizational principles, it becomes crucial to update the way of treating patients' information, emphasizing that professionals and institutions are only their custodians.

Professionals who come in contact with information re only authorized to do so because of their professional need, not the right to use them freely. Therefore, professionals should only have access to information that contributes to the assistance offered by them to the hospitalized patient [21].

It should be emphasized that the guarantee of confidentiality is a factor of adherence to therapy through the bond of trust with health professionals, as well as the basis for the autonomy of the subject representing a protective mechanism for the exercise of freedom itself. Confident that their information will not be disclosed without their consent, patients feel freer to express their particularities, making health decisions without fear of judgment or reprehension about intimate issues. From this perspective, professional secret is considered essential to establish a relationship of ethics and trust between the patient and the health professional [20,22].

Relationships in the area of health are impersonal (between users and staff), but these are often configured as an unequal interdependence, since the professional, because he/she holds the knowledge of the treatment, has greater power before the patient. In this way, communication with the user of health services can be neglected if the professional feels as the "owner" of that power. Attitudes such as treating one patient in front of another user can be understood as disrespectful, causing distress and pain for both the recipient and the one who watches the procedure. It is necessary to think about alternatives that may favor a more responsible and ethical care [23].

Given the result revealed by the participants of this study, it is understood that health professionals could, in addition to respecting the ethical and legal rights of patients, show them attention, respect and understanding about the situation experienced in the hospital environment, providing information and clarification to which they are entitled and by encouraging their participation in decisions about treatment and care. The more informed the users are, the greater autonomy they will have to make decisions or participate in the decisions that concern them, and it is fundamental to recognize patients as citizens, subjects of their own will and of their own care [24].

The discussions highlight the need for a pact based on ethical bases, and it is necessary to clarify the definition of privacy and confidentiality to health professionals and patients. The latter need more information on these terms, and professionals, aware of their definitions, will be better able to provide such information for the qualification of assistance in these respects. The health team leader should include these issues as priorities when planning care actions [1,22].

It is understood that health care services, especially hospitals, may not be properly organized to preserve users' right to privacy and confidentiality. However, the need for care by users can not be accompanied by disrespect for their basic rights as citizens. Therefore, it becomes extremely necessary to preserve their dignity, that is, to ensure their privacy and confidentiality [25].

Final considerations

The results of this research demonstrated that users have ambiguous ideas of what privacy and confidentiality are. Because they do not adequately understand these terms, they also do not understand their rights regarding these aspects in the health care services. Respondents stated that they did not feel disrespected and did not show indignation at situations involving these issues during hospitalization. In addition, the participants

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showed passivity and acceptance in their speech concerning the care received.

With respect to the conformism and passivity demonstrated, it is pointed out that, with information and clarification about rights, these problems could be minimized. Many patients conform to or accept almost all interventions without challenging them because they are not aware of their rights. Being aware, they would tend to participate actively in their therapeutic process.

Therefore, some reflections and challenges arise from the results achieved by the present study, requiring health professionals, managers, administrators and society to change posture when dealing with the issues discussed. Basically, users of health services need to be made aware of their rights during the admission process; the physical structure, material and human resources of the hospital need to be reviewed by the responsible authorities; and health professionals should reflect on their practices regarding issues concerning users' privacy and/or confidentiality.

Although the hospital has deficiencies in the physical structure and in material and human resources, it is emphasized that many of the negative results of this study could be reversed by simple actions of the professionals involved with the assistance to the hospitalized patients.

We conclude that the user of health services suffers from the simple fact of having to be hospitalized and, the more negative factors are present in this process, the greater the suffering of the user. The perception of the interviewees in this study can not and should not be generalized to other contexts, but it certainly serves as a basis for future similar investigations on the themes studied, making it possible to review the dimension of practices in health care.

This study derives from the final paper in the "Privacy and confidentiality in health care from the perspective of users of a general hospital" course, *at the State University of Rio Grande do Norte ("Universidade Estadual do Rio Grande do Norte" - UERN).*

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Participation of the authors

All authors contributed substantially for the conception, planning, data analysis and interpretation, draft elaboration, critical review of the contents and approval of the final version of the manuscript.

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Research

Annex

Semistructured Interview Script

Government of the State of Rio Grande do Norte
Rio Grande do Norte State University (Universidade do Estado do Rio Grande do Norte)
Advanced Campus Prof. Maria Elisa de Albuquerque Maia
Nursing School

Study: Privacy and confidentiality in health care from the perspective of users of a general hospital

Coordinator: Ma. Janieiry Lima de Araújo

Interviewer: Danyllo do Nascimento Silva Junior

Semistructured Interview Script

Personal Data

Sex: _____ Birth date: _____

Municipality or Residence: _____ Zone: Urban ( ) Rural ( ) Age: _____

Skin Color: White ( ) Brown ( ) Yellow ( ) Afro-descendant ( )

Other ( ), specify _____

Do you work? Yes ( ) No ( ) Retired or beneficiary of social security ( )

Occupation: _____ Religion: _____ Marital Status: _____

Education: _____ Family income: _____

HOSPITALIZATION DATA

Date of admittance: _____ Sector of hospitalization: _____

Time in hospital at present: _____

Reason for present hospitalization: Clinical treatment ( ) Surgical treatment ( ) Delivery ( ) Diagnostic investigation ( ) Other ( ) _____

Type of accommodation: Individual bedroom ( ) Double bedroom ( ) Triple bedroom ( ) Quadruple room ( ) Hospital corridor ( ) Other ( ) _____

Interview Script

1 – Can you remember a situation in which you were ashamed (embarrassed) during your hospitalization?

2 – When the professional team provides you care, if there is a need to expose any part of your body, do they ask for authorization? In this situation, do you prefer to be alone?

3 – Have you ever needed anyone to bathe you? How was that bath? How did you feel?

4 – Have you ever heard a professional speak information about you or about other users to others aloud? What do you think about this?

5 – Do the professionals ask your permission to pass information you gave during the hospital stay to others in the team? What do you think about this?

6 – What do you understand by something being confidential?

7 – What do you understand by privacy?

8 – Can you identify any situation you went through during this hospitalization that represents a disrespect to your privacy?

9 – Can you identify any situation you went through during this hospitalization that represents a breach of confidentiality?