

## Nurses' actuation over the patients' rights: decision making, identity and personal autonomy

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### ABSTRACT

Study that aimed to verify the nurses' perception about their actuation over the patients' rights, considering the foundations: decision making, patient's identification and personal autonomy. Quantitative, descriptive-observational and cross-sectional study, carried out at the University Hospital of Brasília-DF. Data were collected from the application of a specific tool for the proposed objective already validated, to 128 nurses. Descriptive statistical analysis and *Wilcoxon's* non-parametric test were carried out. It was noticed that the nurses perceived themselves acting in defense of the patients' rights in all foundations analyzed being the personal autonomy the most exercised and the favoring information for decision making as the least exercised. The study enabled verifying which foundations of the patients' rights are perceived as the most respected, in addition to producing questionings about the theoretical knowledge that the nurses possess on the concepts and the application of these foundations.

**Descriptors:** Ethics, Nursing; Patient Rights; Personal Autonomy; Bioethics.

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Received: 03/24/2018.

Accepted: 11/21/2018.

Published: 12/31/2018.

### Suggest citation:

Ramos AA, Bampi LNS, Lunardi VL. Nurses' actuation over the patients' rights: decision making, identity and personal autonomy. Rev. Eletr. Enf. [Internet]. 2018 [cited \_\_\_\_\_];20:v20a54. Available from: <https://doi.org/10.5216/ree.v20.52105>.

## INTRODUCTION

The advances in scientific and technological advances have marked the most developed societies, having an impact on the most diverse areas, among them the health<sup>(1)</sup>. It's undeniable that such advances contributed to save lives, by revolutionizing the quality of life and the human longevity<sup>(2)</sup>, however, provided the health professionals with a interventionist power ever imagined. In this scenario, patients have become to demand that their views would be taken into account in the clinical decision making process. This attitude promoted a change in the clinical relation, traditionally vertical and infantilized, paternalist, in which the patient obeys the doctor, for a new, more horizontal and democratic relationship, in which the patient's participation is active and questioning<sup>(3)</sup>: the autonomist.

The discourse about autonomy is based on the modernity, on the recognizing of the human dignity and of the capacity that the reason and the will provide to the person to make free choices, to self-determine<sup>(4)</sup>. The Charter of Patients' Rights, of 1972, created in the United States<sup>(5)</sup>, was one of the legal tools that contemplated the autonomy as attribute of the sick human being, considering it capable to decide freely about itself, from the rationalization of the information about its clinical condition, possible options of choice and values involved.

The Bioethics has been, since the middle of the last century, as discipline capable of assisting in the discussion about the human conduct in the areas of health and life sciences, since it interprets in the light of moral values and principles<sup>(4)</sup>. The concerns over the ethical aspects in providing healthcare are not reduced to the norms contained in the legislation or in the professional ethics codes, but understand the respect to the individual as social being, admitting that its essence is the freedom, with commitment and responsibility<sup>(6)</sup>.

The Nursing, such as the Bioethics, also includes the human dignity and autonomy concepts to define the care from an ethical perspective<sup>(4)</sup>. Currently, the nursing care ethical essence can be defined as: provide the care in response to the vulnerability of the human being in order to maintain, protect and provide the dignity as much as possible<sup>(7)</sup>. Respect and provide the autonomy of the patient is an exercise that requires the realization of pressuppositions already defined in the Bioethics literature: "tell the truth; respect the privacy; protect confidential information; obtain consent for interventions and, when requested, help in decision making"<sup>(8)</sup>.

Despite this, the literature says that the compliance with the principle of the respect to the autonomy in Nursing is a polemic issue and an important problem for the Bioethics<sup>(4)</sup>. The nurses, mainly in the hospital environment, have difficulty in putting into practice the principle of autonomy for different reasons, either by the lack of clarity about the meaning and scope of the principle; or by the mistaken understanding of that exist divergence between the principle of autonomy and the obligation to take care of<sup>(4)</sup>. There is a responsibility by the nurses to provide the sick human beings' dignity and autonomy through their interaction with the health team<sup>(9)</sup>. This responsibility is mentioned in Code of Ethics of the Nursing Professionals in the list of duties: "respect the exercise of the autonomy of the person or of the legal representant in decision making"<sup>(10)</sup>.

As such, the ethical, moral and deontological importance of the nurses to develop actions that enable the respect and the promotion of the autonomy and the rights of patients in the care practice becomes clear. However, it is not clear whether these professionals can carry out them<sup>(4)</sup>, or they perceive themselves acting in the sense of implementing them. A Brazilian study<sup>(11)</sup> presented a tool capable of verifying whether the nurses was acting before the defense of the patients' rights from their own perceptions. This tool contributes to the study of the theme patient's autonomy.

Use this tool<sup>(11)</sup> to deepen the knowledge about the daily practice of the nurses, in the sense of identifying postures that could contribute or not with the respect to the autonomy and the patients' rights becomes essential in reflecting the relevance and the responsibility of the nurses in health assistance. In addition, it is already recognized that health treatments and care when are qualified as respectful and worthy by the patients, have the potential to present better results<sup>(9)</sup>.

The results of the present research may compose the theoretical reference of respect to the patient's autonomy, from nursing care. Under that perspective, the research was developed in order to verify whether the nurses perceive themselves respecting the patients' rights in the hospital care practice, considering the foundations: decision-making, identity and personal autonomy.

## METHOD

Study of quantitative approach with descriptive-observational method with cross-sectional cut in time-space. Research carried out in a University Hospital of Brasília-DF. The data collection occurred from June to December of 2016. One hundred and twenty-eight nurses participated in the research. The sample calculation was defined by simple random sampling, considering 250 nurses, which exercised their labor activities in hospital assistance sectors, outpatient and diagnosis to adult patients. The sampling error considered was 5%.

Two tools were used for the data collection. The first, consists of a specific tool developed and validated<sup>(11)</sup> to verify the "perception of nurses about their actuation in regard to the clients' rights". This tool consists of 13 questions with operationalized answers in *Likert* scale, ranging from 1, never, to 5, always. The tool validation was verified by factor analysis and the *Cronbach's Alpha* tests. The factor analysis grouped the questions of the tool in four different constructs, representing different facets perceived as for the rights<sup>(11)</sup>. The constructs proposed were defined conceptually as: preservation of the individuality, including implemented actions to ensure the respect for the patient's intimacy and individual characteristics; respect to the client's autonomy, which implies the right of the client to self-determination; personal identification, referring to client's right to be identified individually with respect to be able to identify personally the professionals with whom it has a relationship; and, information for the decision making, such as the client's right of the client to be informed, in order to underpin the decision-making<sup>(11)</sup>.

A second tool, containing questions related to gender, age, training time, post-graduation training, time of service and local for development of activities in the Hospital studied was used to characterize the sample studied. The tools for data collection were self-administered and for orientation about the filing there was a brief instruction in the sheet of presentation.

Data were analyzed using the *IBM Statistical Package for Social Sciences (SPSS)* program, version 24.0. The variables considered in the data analysis were: age, gender, training time, to have post-graduation, time of work in the institution, actuation unit in the studied Hospital and presence of other employment bond. The sample characterization was carried out through descriptive analysis, using the absolute and relative frequencies. The study dependent variable – nurse's perception about its actuation before the patients' rights – was measured as of the four constructs proposed in the cited tool<sup>(11)</sup>: preservation of the individuality, respect to the patient's autonomy, personal identification, and information for the decision making. The means and standard deviations

of the scores obtained in the application of the tool by construct were calculated. The average values of each construct were compared with each other. For such, the non-parametric statistical analysis was used. The *Wilcoxon* test for comparison between two non-matched samples, considering  $p > 0.001$  was applied. From this comparison it is possible to see which dependent variable construct was more considered in relation to another.

The respect to the ethical requirements was guided by Resolution no. 466/2012 of the National Health Council. The project was cleared by the Research Ethics Committee of the Faculty of Health Sciences, of the University of Brasília, and was approved in April 2016 (Opinion 1.484.752). The acceptance in participating in the research was confirmed by the participant by signing the Informed Consent Form (TCLE).

## RESULTS

The studied sample was comprised mostly of women (83%) under 40 years old (83%). Most participants had professional training time less than 10 years (73%), having as the highest academic degree referred the *lato-sensu* postgraduate (83.6%). Predominantly, the nurses worked in hospital units of internment (77.3%), with time of service in the institution between two and four years (46.9%) and with employment bond only with the institution where the research was conducted (63.3%).

The evaluation of the nurses' perception about their respect for the patients' rights was carried out from the application of specific tool<sup>(11)</sup>. The tool is divided into four dimensions and/or constructs that represent the foundations of the respect for the patients' rights. Considering that the variation of answers in the *Likert* scale of the instrument was 1 (never), 2 (rarely), 3 (sometimes), 4 (in their majority) and 5 (always). Table 1 shows the central trend and the dispersion of scores obtained with the instrument application.

**Table 1:** Mean and standard deviation by question and by instrument construct – Nurse's perception regarding its respect for patients' rights. Brasília, DF, Brazil, 2017.

	N	Mean	SD
<b>Information for decision-making</b>		<b>4.07</b>	<b>0.27</b>
I provide the client with understandable information about the name of the medicines administered	128	4.35	0.84
I provide the client with understandable information about possible benefits of the established therapy during its hospitalization	128	4.31	0.68
I provide the client with understandable information about the possible effects of the administered medicines	128	4.07	0.84
I provide the client with understandable information about possible risks of the established therapy during its hospitalization	128	3.88	0.95
I provide the client with understandable information about possible risks of the diagnostic actions during its hospitalization	128	3.72	1.00
<b>Personal identification</b>		<b>4.31</b>	<b>0.34</b>
I identify myself to my client under my care through prior presentation (informing my name, position and function)	128	4.55	0.71
I call the client by its name and surname	128	4.07	1.07
<b>Respect for the client's autonomy</b>		<b>4.64</b>	<b>0.03</b>
I respect the client's right to consent or refuse nursing procedures performed at him	128	4.68	0.52
I respect the client's right to consent or refuse therapist actions to be performed at him	128	4.62	0.69
I respect the client's right to access to his medical record	128	4.63	0.80

## DISCUSSION

In the construct, analysis-Information for decision-making it is noticed the nurse's perception about its attitude towards providing understandable information to the patient so that the same take a decision about the

health care. The decision-making is the patient's right to decide and elect, which is the best choice, among the existing, and possible, by considering its own convictions and regarding its own life project, without the interference of third parties<sup>(8)</sup>. Based on the ethical principle of the respect for the autonomy, in the autonomous decision-making the individuals must act intentionally, with knowledge and without external influences that exercise control over their actions<sup>(8)</sup>.

The average obtained in this construct points out that in their majority, nurses provide information that subsidise the patients' decision-making, with these information in most cases related to the name of the administered medicines (4,35), and, in a minority, on the risk of the diagnostic actions (3,72).

A systematic review<sup>(12)</sup> identified the nurse's role in the making-decision process in treatment of cancer people. Providing information to the patient is one of the nurse's main roles in clinical practice. Patients, caregivers and relatives identified the nurses as a safe and reliable source of information, especially for treating, of the possible diagnostic actions, of the treatment trajectory and of the diseases symptoms, including the prognosis. The reliability of the information provided by the nurses are originated, probably, from the close relationship that the professional develops with the patient, due to the high number of daily hours spent on giving care<sup>(13)</sup>.

The Code of Ethics of the Nursing professionals ratifies the obligation of providing information for patients when determine, in its article 39, the professional duty of "Clarifying the person, family and society, regarding the rights, risks, benefits and interurrences about the nursing assistance", as well as, "Orienting about the preparation, benefits and consequences resulting from exams and other procedures, respecting the right of refusal of the person or its legal representing"<sup>(10)</sup>. Although it is a professional obligation, the providing of information for the decision-making obtained smaller averages in the questions whose content was about the risks of the established therapy, of the diagnostic actions and of the medicines administered. The omission by nurses of information about the risks inherent in treatment or the consideration only from the benefit facts of the therapy suggest that this professional values the principle of beneficence at the expense of the person's autonomy. By knowing the importance of the therapeutic, diagnostic and drug actions, the attitude of omitting information is based on the idea that the patient could refuse submitting itself to them if he was aware of the known adverse risks and effects.

The role of the nurse in the patient's decision-making was object of an international research<sup>(14)</sup>, which noticed that these professionals actuate in the patient's educative/informative process clarifying the treatment plan passed on by the doctor, with more accessible language. In this study, the patient's defense, the patient information sharing to the multi-disciplinary team, the symptoms and adverse effects of the established therapy and the psychological support were recognized as the nurse's roles in the sharing decision-making process.

In Brazil, nurses still feel weakened to act in situations that involve the patient's making-decision, because the power of decision over the therapeutic conduct of patients is still medical team-centralised<sup>(15)</sup>. There are barriers, already identified in the literature, that limit the nurse's participation in the making-decision process<sup>(13)</sup>, being these related to the clinical practice, since it do not exist standardization of activities that favor the assistance uniformity; to the patient, when it is not prepared emotionally to receive information or prefer to receive them from the physician; to the institutional policy, when the institution does not favor the nurse's

participation in the process, requiring medical supervision to the detriment of the collaboration between doctors and nurses; to the professionals, when the nurse does not hold the necessary knowledge and the training and present little professional experience; to institutional management, when the institution does not provide adequate resources or does not support the nurses to carry out the activity<sup>(13)</sup>.

The second construct analyzed referred to the nurse's perception as for the respect for the patient's rights, regarding the personal identification as submitted to the health and Nursing care. The participants in this research perceived themselves as respecting frequently for the assumptions of personal identification, which construct obtained mean 4.63, with standard deviation close to zero (0.03). The Nursing Professional Ethics Code makes clear that "the respect for the human rights is inherent in the exercise of the profession, which includes rights (...) to the dignity and to be treated without distinction (...)"<sup>(10)</sup>. This reference in the Resolution text<sup>(10)</sup> underlies the reasonability so that the nursing professional can relate to the patient who is under care, and call him by his name and surname, since these attitudes ensure a respectful positioning before the person's dignity. By respecting for the person's dignity, the one recognizes its unicity, its individuality and its biography, known within the civil society from the attribution of a name and a surname.

The Letter of Health Care User's Rights<sup>(16)</sup> assures citizens the basic right to the dignified entering in public and private health systems. One of its principles ensures a welcoming attendance, free of any way of discrimination. So that this principle can be met, the norms establish that it is guaranteed for the patient: "In addition to the identification of the name and surname it must exist in all user's identification document a field to record the name by which the individual prefers to be called". In addition, that the "professionals e are responsible for their service be identified through visible and legible badges"<sup>(16)</sup>.

The nurse's attitude of calling the patient by its name shows the recognizing of its individuality and singularity. An adequate treatment, based on the respect is important and indispensable to create a link with the person to be cared for<sup>(17)</sup>, is the first step to build a relationship between the patient and the nurse based on a respectful dialogue involving commitment and valuation with the human being. The attitude of calling the patient by the name relates to the development of a humanized care. The dialogue, the information given to the sick person and the patient's identification by the name are described as actions that lead to the humanization of care<sup>(18)</sup>.

Following on from the analysis, the third instrument construct that composes the respect for the patients' rights names – respect for the autonomy of the client. The questions related to this construct make reference to the acquisition of the patients' consent by the nurses, in order to submit to therapeutical actions and to nursing procedures. The nurses' attitude of requiring consent to carry out therapeutical actions and nursing procedures obtained mean 4.62 and 4.68, respectively. The action to enable access to the medical record obtained mean 4.63.

The informed consent is the basic tool that consolidates the patient's autonomy<sup>(19)</sup>. At requesting the patient's consent to carry out activities related to the care, the nurse recognized in it its capacity to take autonomous decisions related to the health and well-being<sup>(20)</sup>. For that, the patients need to receive information about their clinical condition, therapeutic options available and the risks and benefits of the interventions proposed<sup>(19)</sup>.

So that the consent can express the actual autonomy exercise, the patient should demonstrate the capacity to understand the information, to decide without interference by the others and in an intentional way by granting authorization for the professional<sup>(8)</sup>. As it is considered as a communicative process, the acquisition of consent requires that the professionals have communication skills that can help the patient understand its clinical situation even before its fragility and vulnerability condition as a sick person<sup>(19)</sup>.

The results of this study showed that the nurses perceive themselves by respecting for the patient's right to consent therapeutic actions and nursing procedures. Few studies present data on the engagement of the nurse in the consent acquisition yet<sup>(20)</sup>. Studies carried out with patients point out that these persons not always felt wellinformed when making decisions<sup>(21)</sup> or perceived the professional's attitude as a mere formality<sup>(19)</sup>.

Considering the assumptions for the consent acquisition, there is undoubtedly the relation existing between the constructs "information for decision-making" and "respect for the autonomy of the patient" of the data collection tool, since this last is preceded by the first. In this sense, to verify whether exists any significant difference of the participants' performance between these two constructs, we applied the *Wilcoxon* test. Thus, it was noticed that the construct "respect for the autonomy of the client" is perceived as more exerted in relation to the "personal identification" ( $p = 0.001$ ) and to the "information for decision-making" ( $p < 0.001$ ).

Facing this result, we should which is the understanding of the participants about the term "consent", since the practice perceived does not harmonize with the prerequisites required by the existing theory. However, the literature can sustain the understanding on this situation. In the health area, a concept is widespread diffused: the implicit consent supported in the professionals' expectancy of that the patient is waiting for certain procedures to be carried out while he is under health care. For this reason, the act of consenting is limited to ask a specific question to the patient and wait its permission, providing a minimal explanation about the actions to be developed<sup>(22)</sup>.

A study<sup>(23)</sup> about the conception and the use of the implicit consent in the carrying out of nursing procedures point out that the most interviewed nurses used it before carrying out the nursing procedures, and considered the no objection by the patient to the continuity care as a form of consenting. One of the reasons for the implicit consent use is the tolerance of the sick person to the lack of information. The conformed patient's position leads to non-questioning about the procedures and, by they do not be questioned, the nurses limit themselves to provide some information that consider adequate. The implicit consent has used to carry out routine nursing care, seen as a general consense in the nursing practice<sup>(22)</sup>, which becomes worrying, since such action may not benefit the autonomy of the patient and its right of consenting or refusing nursing procedures.

The nurses are the most reliable professionals by the patients to answer questioning and clear doubts<sup>(19)</sup>, then, the nurse is emphasized as the fundamental element in the carrying out of the consent process and, consequently, in the incentive to the patient's self-determination. The continued and extended contact with the patient can be used as opportunity to strengthen with it the existence of its rights and its personal prerogative of self-determination.

The detailing of the nurse's perception in this study, made possible not only the verification of which foundations of the respect for the patients' rights are perceived as more respected, as well as emerged the questioning about the theoretical knowledge that the nurses have about the concepts and operationalization of

these foundations. That is, the results found might have suffered interference, to a certain extent, to the lack of clarity about the concepts on which the foundations of the patient's rights are based, or even of the own des-knowledge of the nurses. The literature used evidenced different situations in that such concepts were mistaken or were being operationalized in an incoherent manner. This fact should be considered as limiting point in this study.

## CONCLUSION

It was noticed in this study that the nurses perceive themselves acting before the respect for the patients' rights in all the foundations evaluated. This result helps to ratify the moral value of the nursing profession and reinforces which ethical attitudes and behaviors need to be implemented, in order that the patients can have their rights respected.

Another important fact is the need to deepen the knowledge about the care value as ethical instrument. This can be expected to lead to a reflection about the attitudes adopted in the clinical practice by the nurses, as well as to the interest of the scientific community in deepening investigations in the area of Ethics in Nursing and Bioethics, in the sense of expanding the theoretical reference in these themes.

The limitation identified can be overcome with the conducting of complementary studies that use qualitative methodological designs capable of evidencing the nurses' knowledge about the foundations of the patients' rights and the practical applicability in providing healthcare, helping to clarify questionings and provide more content to this debate.

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