

**UPDATE**

## Patient ombudsman: rights in health care

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**Abstract**

This article aims to analyze the role of the Patient ombudsman in the implementation of patients' rights, reflecting on their application in Brazil. This is a theoretical research on the subject and its differences in relation to the human rights of patients. It has concluded that the proposed model for Brazil emphasizes the role of local ombudsman, especially in the hospital environment, but also defends the institution of regional professionals to deal with primary care patients. However, it is suggested that the regional one be optional, because the hospital is the major focus of adverse events. Also, it should be noted that the authorization of the ombudsman is provided by law, which establishes specific prerogatives, such as their autonomy and independence, appropriate qualification, and efficient investigation of complaints.

**Keywords:** Ombudsman. Patients. Human rights. Health system. Patient advocacy. Patient rights.

**Resumo****Ombudsman do paciente: direitos nos cuidados em saúde**

Este artigo analisa o papel do ombudsman do paciente na implementação de seus direitos, refletindo sobre sua aplicação no Brasil. Trata-se de pesquisa de cunho teórico sobre o tema e suas diferenças em relação aos direitos humanos dos pacientes. Conclui-se que o modelo proposto para o Brasil enfatiza a atuação de ombudsman local, notadamente no ambiente hospitalar, mas também defende a instituição de profissionais regionais, para lidar com pacientes da atenção primária. Contudo, propugna-se que o regional seja facultativo, em razão de o hospital ser o ambiente com mais adversidades. Ainda, destaca-se que a autorização do ombudsman seja dada por lei que estabeleça prerrogativas específicas, como sua autonomia e independência, qualificação apropriada e apuração célere de reclamação.

**Palavras-chave:** Ombudsman. Pacientes. Direitos humanos. Sistema de saúde. Defesa do paciente. Direitos do paciente.

**Resumen****Ombudsman del paciente: derechos en los cuidados de la salud**

Este artículo analiza el papel del ombudsman del paciente en la implementación de sus derechos, reflexionando sobre su aplicación en Brasil. Se trata de una investigación de naturaleza teórica sobre la temática y sus diferencias con relación a los derechos humanos de los pacientes. Se concluye que el modelo propuesto para Brasil enfatiza la actuación del ombudsman local, principalmente en el ambiente hospitalario, pero también defiende la institución de profesionales regionales, para lidiar con pacientes de la atención primaria. No obstante, se propone que el regional sea facultativo, debido a que el hospital es el mayor foco de eventos adversos. Por otra parte, se destaca que la autorización del ombudsman debe darse mediante una ley que establezca prerrogativas específicas, como su autonomía e independencia, una calificación apropiada y un análisis célere de los reclamos.

**Palabras clave:** Ombudsman. Pacientes. Derechos humanos. Sistema de salud. Defensa del paciente. Derechos del paciente.

Declararam não haver conflito de interesse.

Patient rights became recognised in the 1970s; however, for a number of countries, patient rights legislative prediction had a real milestone only in the 1990s<sup>1</sup>. The passage of laws on patients' rights in certain countries stimulated the perception that, although the law was an essential instrument to ensure those rights, it was not enough. As a consequence, specific instruments were instituted, with emphasis on the patient ombudsman, whose function is to promote such rights, through the investigation of complaints made by patients<sup>2</sup>.

The figure of the ombudsman appeared in Sweden 210 years ago, in order to identify which person had the right and power to speak on behalf of another person or persons. However, ombudsmen in the health area were not created in Sweden, but in Finland in 1992<sup>3</sup>. Currently, the position exists in the United Kingdom, Austria, Finland, Israel, Greece, Hungary, Norway<sup>4</sup> Belgium<sup>5</sup>, New Zealand and Canada<sup>6</sup>.

Brazil, unlike many countries with legislation on patient rights, does not have a national law on the subject. It has only sparse legislations that establish some rights, such as the monitoring of pregnant women, children, the elderly and the disabled. In addition, there is the right to self-determination of persons with disabilities, based on the *Estatuto da Pessoa com Deficiência* (Statute of the Person with Disabilities). It is perceived that the country lacks an efficient institutional culture, delaying the discussion among Brazilian professionals, which contributes to increase the vulnerability of people affected and generates worse results in health.

In addition to legislative insufficiency, Brazil does not have instruments to ensure the rights of patients, because despite the lack of specific laws in the area, the Ministry of Health has issued the *Carta dos Direitos dos Usuários da Saúde* (Charter of the Rights of Health Users)<sup>7</sup>, which has no force of law but could be used, as is the case in Canada, with the *Carta de Direitos e Liberdades* (Charter of Rights and Freedoms)<sup>6</sup>, which has fostered the establishment of means to protect patients.

In order to avoid ambiguities about the object of this article, the patient ombudsman should be distinguished from the health ombudsman or the hospital ombudsman because, although they have the capacity to listen to the patient, they do not promote their rights or investigate their complaints. On the other hand, although the ombudsman is impartial in the investigation of complaints of the various people involved in health care, the ombudsman has the central role of disseminating information about the rights of the patient, legitimise their complaints and mediate eventual

conflicts. The ombudsman is a specialist in dealing with complaints, emphasising the adversities of the claims and the means to solve them<sup>4</sup>.

This article analyses the role of the ombudsman in the defense of patients' rights, with the purpose of formulate a suitable proposal for this practice in Brazil. It is a theoretical research, based on the investigations of Stephen and Fallberg<sup>4</sup>, Molven<sup>2</sup>, and Colleen and May<sup>6</sup> on patient ombudsman. It is also based on the theoretical formulation of Albuquerque<sup>1</sup> and Cohen and Ezer<sup>8</sup> on patient human rights. It is important to note the scarcity of research on the subject in Brazil, in the legal area as well as in bioethics and health care.

One of the methodological steps was to seek a bibliography about this type of ombudsman, and then references about their rights in order to create a theoretical framework, distinguishing the patient's rights from those of health users.

Subsequently, the role of patient ombudsmen and their work in other countries was analysed in order to understand the diversity of the ombudsman's work. The Finnish experience is presented in this article because Finland was the first country to envisage the role of patient ombudsman in law. The Austrian experience is presented here because of its remarkable investigation of complaints. Finally, the article elaborates a proposal for reflection on the performance of the patient ombudsman in the country.

### Distinction between patient and user

As this article deals with the ombudsman as the one who defends the rights of the patient, it is essential to expose the distinction between the rights of the patient and the rights of health care users. In Brazil there is a great deal of confusion in the use of the terms "patient" and "user" and their related rights, from which derives the mistaken understanding that they could be reciprocal substitutes and also causes the serious lack of legislative prediction of specific rights of patients in the country. There is a great predilection for the term "user" in the sphere of the *Sistema Único de Saúde* (Unified Health System - SUS), as if such a conception could also include that of a patient. This confusion, expressed in the *Carta dos Direitos dos Usuários da Saúde*<sup>7</sup> (Charter of the Rights of Health Users), is not only semantic, it also brings important juridical questions and understanding of health care.

Patient is the person in health care, and the user is the person who have access to a health system, being a patient or not. The patient has

an essentially personal relationship with health professionals, while the user has an impersonal relationship with the service; thus, patients' rights are the rights of all under health care, and the rights of users relate more to their contact with a particular service. Patient and user are distinct conceptions, and each deserves reflections and its own studies.

Patients' rights, for example, are related to the clinical encounter, the patient's right to consent or refute health care, to seek second opinion, not to feel pain, to choose where to die, among others. The rights of users concern the provision of service, such as the right to obtain accurate and easily accessible information on the places of care and participation in their monitoring and evaluation<sup>9</sup>.

The criticisms in Brazil regarding the use of the term "patient" are focused on two arguments: the first is etymological, indicating that this word denotes passivity and does not contemplate the political dimension and social participation of those who use health services. In addition, the origin of "patient" expresses the idea of vulnerability, naming those who are fragile, because the term originates from the Latin word *patior*, which means "to bear" or "to suffer"<sup>10</sup>. If, on the one hand, the criticism considers the fragility that emanates from the word "patient" to be a reason to replace it, the word is maintained, on the other hand, because it is significant and opportune to highlight the peculiar condition of increased vulnerability of "patient".

As Morin points out, human beings use language and often create mental products or ideas that mask reality, making us prioritise the "idea" to the detriment of the "real"<sup>11</sup>. The attempt to mentally create a patient who is not fragile consists in the negation of the real, insofar as it superimposes the effective condition of those who are sick to the transcendent idea that disease does not weaken people. However, recognising the patient's vulnerability does not mean denying or mitigating their autonomy or capacity for social participation.

The second criticism claims that, despite arguing that "user" demarcates participatory action (giving it a social and active character), the global point of view is the activism of patients, not the activism of users. It is emphasised that the political and public performance of individuals and groups who want to claim rights and transform health services can be termed "patient activism"<sup>12</sup>, "patient movement"<sup>13</sup> or, according to Mol<sup>14</sup>, "paciensism" by analogy to feminism. It is noted that safeguarding the rights of people in care is not carried out by the user, but by the patient, who carries with him or her the force of activism.

## Rights of patients from the viewpoint of human rights

As seen in the previous topic, those who are under health care can fit into the category of patient and / or user. The list of patient rights derives from the prediction of international human rights standards for patients, studied by Albuquerque<sup>1</sup> and Cohen and Ezer<sup>8</sup>.

Patients' rights and human rights are based on four aspects: firstly, patients' rights focus on people in a condition of increased vulnerability. Second, it concerns the severe asymmetry of power in the patient-professional relationship. Historically, the decision on health care has been in the hands of the physician, and this imbalance may sustain authoritarian and patriarchal behaviour<sup>15</sup>. The third aspect emphasises the need to give voice to the patient, providing him or her with tools, such as human rights, to stand his or her ground and actively participate in the claims of his rights<sup>16</sup>. Finally, the patient should not have his or her citizenship reduced: The patient should not be seen merely as a body or a disease, but as a person, whose identity is constructed in a subjective way and permeated by values, beliefs and interests<sup>17</sup>.

Considering these four aspects, it is clear that human rights are the most appropriate means to protect vulnerable groups and redistribute decision-making power during a clinical encounter<sup>15</sup>, as well as to ensure the treatment of the patient as a person, since the indivisibility of the patient's rights prompts the association of the right to health with other aspects, such as privacy, non-discrimination and prohibition of possible inhuman and degrading treatment.

This model of care is based on the patient<sup>18</sup>, on the logic of care<sup>14</sup>, and not on the professional, and it had being incorporated into the health discourse at the beginning of the 21st century. It is commonly understood by its negative, that is, by what it is not: it is not centred on disease, hospital, or doctor. It can also be understood by its positive characteristics, such as respectful and responsive care, taking into account patient preferences, needs and values in order to guide clinical decisions<sup>18</sup>.

In the same direction, the logic of care differs from the logic of the market or the logic of choice, which permeates the consumer relation. According to the first, care is an interactive and continuous process between professional, patient and family members and it can be modelled and remodelled, depending on the results<sup>14</sup>. The market logic considers the treatment simply as a product offered to the consumer. It is a supply and demand process.

In order to identify the human rights treaties that apply to the patient, Albuquerque<sup>1</sup>, the same way that Cohen and Ezer<sup>8</sup>, present the following list of the rights: life; health; information; privacy; liberty; not be subjected to torture, cruel, inhuman or degrading treatment; not be discriminated against. From these, other more specific rights have been derived, with the purpose of making possible their incidence in health care. Thus, the following list of rights was reached:

- right to count on companions in consultations and hospitalisations;
- right to quality care, with adequate and trained professionals;
- right to safe care;
- right to information, including the right to receive of a list of medicines;
- right to make decisions about their health care;
- right to refuse health care;
- right to be informed about the name of the professionals who participate in the service;
- right not to be discriminated against;
- right to confidentiality of information;
- right to privacy;
- right of access to medical records;
- right to make choices about the conditions of his or her death;
- right to manage pain;
- right to be informed about adverse events;
- right to have representative (s)<sup>1,19</sup>.

Next, more questions about the work of the patient ombudsman will be discussed.

### Patient ombudsman in the protection of the patient's rights

This topic is based on the studies of Mackenney and Fallberg<sup>4</sup>, Molven<sup>2</sup> and Flood and May<sup>6</sup> on the subject. Patients' rights include, among others, the right to complain, which presuppose an instrument that allows a swift, accessible, non-costly and impartial investigation<sup>6</sup>. Thus, the patient ombudsman is the one who investigates the patient's complaints, in order to guarantee rights and increase the quality of health.

Complaints and their investigation are significant tools to change the culture of health, however, it is not an expeditious task to convince professionals that they need to change their treatment. Convincingness is easier when the ombudsman relies on scientific evidence and information from clinical practice.

Thus, in addition to receiving and processing individual complaints, the ombudsman must have tools that allow him or her to gather information about adverse events and analyse them with hospital or hospital professionals in order to address their causes. Therefore, it is necessary for the ombudsman to seek patterns of problems in individual cases, in order to detect them and propose systemic changes<sup>4</sup>.

According to Mackenney and Fallberg<sup>4</sup>, there are three central aspects to implement a patient ombudsman model: 1) impartiality and independence; 2) qualification; and 3) attribution. The ombudsman must act independently of the service and the professionals involved, and this autonomy must be established in the regulations to guide his or her action. Ombudsmen must be impartial in the determination of complaints, because if they do not adopt a proper posture, they can lose credibility.

The qualification of ombudsmen presupposes training in legal matters and in the investigation of claims to be brought to the judiciary, as well as in matters pertinent to the clinical context. As for the duties, it is important that ombudsmen have sufficient power to ensure the credibility of their performance and the observance of their role. It is also essential that ombudsmen have access to all records and can legally demand, from all actors involved, compliance with their determinations. In short, the central role of patient ombudsmen is to support, serve and protect the patient individually<sup>4</sup>.

In view of the diversity of patient ombudsman models, two different models will be discussed: the Finnish model and the Austrian one. In Finland, the first country to have specific legislation for patients, the Act on the Status and Rights of Patients issued on 17th August, 1992<sup>2</sup>, creates on section 11 the role of patient ombudsman, who shall be appointed for health care units and may be common to more than one unit. The patient ombudsman tasks are: to guide patients on matters related to the act; help them to understand their right to complaint; inform them of their rights; and act for the promotion and implementation of patient's rights.

According to the Finnish model, every public or private health unit is obliged to indicate a patient ombudsman, which originated more than two thousand professionals in different places of the country. The

central idea of this model is that the dissemination of information influences attitudes, prevents conflicts and, as a result, promotes patients' rights<sup>20</sup>.

The Austrian model focuses on the investigation of complaints. Since 2002, patient ombudsmen services are involved in the patient compensation fund. In 2009, 9,561 complaints were filed and, of these, 5,349 were about hospitals, 917 were about the compensation fund of the patient, and 800 were about doctors. Several hospitals have ombudsman offices for this service, but ombudsmen are usually part of the hospital's management team and perform only quality management. In most cases, the Patient Advice and Liaison Service of the hospital and the ombudsman work together<sup>21</sup>.

According to Mackenney and Fallberg<sup>4</sup>, patient ombudsmen use different instruments to defend patients' rights and settle their claims impartially. Another outstanding aspect concerns the debate on the scope of this professional; whether it should be regional or local. In countries like Israel and Hungary, local representatives simplify the work of the national ombudsman; this, in turn, coordinates the local representatives, as well as systematises the information and the production of knowledge on the subject.

It should be noted that determinations related to patient's complaints present significant results in the resolution of conflicts, considering that the ombudsman has no legal attribution to punish professionals or impose pecuniary reparations. This success can also be attributed to the non-contentious nature of the tasks the ombudsman performs, such as collecting information, accessing records and listening to people involved in conflicts<sup>20</sup>. Indeed, a Canadian survey found that in New Zealand, the disciplinary processes of professionals have reduced their annual cases from 84 to 08 since the adoption of the Code of Rights, a regulation under the Health and Disability Commissioner Act, and a faster expediency procedure<sup>6</sup>.

In Quebec, between 2009 and 2010, more than 98% of patient ombudsmen recommendations were adhered to. Their capacity for persuasion is perceived to have more influence in changing the culture of health services than disciplinary processes or litigation. Thus, it can act as a positive barrier in judicial and disciplinary processes, without being given punitive or contentious nature, which makes providers and professionals more receptive to its recommendations<sup>6</sup>.

Patient ombudsmen are essential to uphold patients' rights and improve the quality of health care. As seen, performance models may vary, and each country adopts the model most suited to their situation. In spite of the choice, the patient ombudsman is one

of the main agents in the promotion of health, and the law becomes dead letter without the establishment of Offices of patient ombudsman<sup>4</sup>.

## Proposal for Brazil

Analysing the highest level of information about patient ombudsmen in Brazil, we looked for information in Google about patient ombudsman acting, using the expression *ombudsman do paciente* (patient ombudsman). Considering the twenty main entrances, only ombudsmen of hospitals and the ombudsman of the *Ouvidoria da Agência Nacional de Vigilância Sanitária* (Ombudsman of the National Agency of Sanitary Surveillance - Anvisa) were identified. All of them mention only the contact for eventual complaint and treat the patient as a user of a service, a problem which has already been discussed at the beginning of this article.

The examples point to something already addressed: a lack of patient-centred approach and his or her rights. In this regard, three hypotheses can be raised: Brazil does not have a law on patients' rights; it confuses the concept of user's right with that of patients (and consumer); and the role played by the ombudsman is limited to collecting complaints and passing them on to competent bodies. In this way, we can see that these ombudsmen do not resemble at all the complex models of patient ombudsmen in other countries.

The role of patient ombudsmen is to defend the rights of the patient, with a legal basis anchored in the human rights of patients, not in consumer laws. In the case of Brazil, the patient ombudsman should assert these rights as it is provided for in the Bill 5.559 /16<sup>22</sup>, which pending in the Brazilian Congress. Thus, it is proposed to insert the role of patient ombudsman in this bill, as described in this article.

As it happens in countries that have already adopted the model, the Brazilian State must take into account the organisation of the health system in the country, constituted mainly by the *Sistema Único de Saúde* (Unified Health System - SUS), legally defined as the set of actions and health services provided by federal, state and municipal public bodies and institutions, direct and indirect administration, and foundations maintained by public authorities<sup>23</sup>. Primary health care in the SUS is done by family health teams, in the Unidades Básicas de Saúde (Basic Health Units - UBS)<sup>24</sup>, whose objective is to attend up to 80% of the health problems of the population, without referral to hospitals<sup>25</sup>.

In addition to the SUS, private health plans are also covered, regulated by the *Agência Nacional*

*de Saúde Suplementar* (National Supplementary Health Agency - ANS). Regarding secondary and tertiary care, according to the *Cadastro Nacional de Estabelecimentos de Saúde* (National Registry of Health Establishments - CNES), 70% of Brazilian hospitals are private, 1% are federal, 8% are state hospitals and 21% are municipal hospitals<sup>26</sup>.

It is reiterated that the patient ombudsman has some basic functions: to promote patient's rights through dissemination of information and swift assessment of complaints, without burden to the patient and without containment or punishment, as well as to increase the quality of health care. Considering these characteristics, it can be seen that patient ombudsmen distinguishes themselves from the SUS' ombudsman office, which focuses only on the SUS's users and does not predispose itself to any of the activities common to patient ombudsmen. The SUS's ombudsman is only responsible for receiving, examining and forwarding complaints<sup>27</sup>. Patient ombudsmen also distinguish themselves from the ANS's ombudsman, whose focus falls only on consumers of health insurance plans<sup>28</sup>.

Health plans' ombudsmen exist to solve issues related to consumers who have already resorted to the usual care services and have not been able to solve their problem<sup>28</sup>. With distinct scopes, the patient ombudsman does not have the desideratum to mitigate the function and importance of other types of ombudsmen but to contribute to the vision of the patient as a person, holder of inherent rights, and to improve the quality of health care.

Considering the conformation and complexity of the SUS and the supplementary health care, as well as their respective ombudsmen, it is proposed the adoption of local ombudsmen in Brazil, with full time status and without conflict of interest. Most of the models studied by Mackenney and Fallberg<sup>4</sup> are required to have a patient ombudsman, and in addition, regional ombudsmen who work with primary care are recommended. Still, studying the Norwegian model, Molven<sup>2</sup> points out that access to the patient ombudsman must be informal and free of charge for the patient.

From the legal point of view, the patient ombudsman will be a private or public hospital employee. In both cases, it is important that the law guarantees certain prerogatives, such as: investigative autonomy in the determination of the complaint; access to all information and records of patients in the hospital, regardless of authorisation; and the possibility of interviewing health professionals or other professionals who can provide relevant information. In addition, the law must establish qualifications for the full exercise of

the function such as professional competence in the legal and health care areas.

As for the role of the ombudsman, it is essential that he or she makes public reports and have legal authority and independence to disclose the reports to professionals and other health care providers, aiming at a culture of patient rights, coupled with the quality of patient care and safety.

In summary, the proposed office of patient ombudsman model for Brazil emphasises its place of work, especially the hospital environment, but also incorporates regional ombudsmen to deal with primary care patients. However, it is proposed that regional ombudsmen be optional, because hospitals are the environment which present more adverse events. It is also worth noting that the creation of the Office of the patient ombudsman in Brazil is created by law that establishes specific prerogatives, such as autonomy and independence, appropriate qualification and speedy determination of complaints.

### Final considerations

Due to a series of factors, such as exclusive focus on users' rights and the patient's lack of knowledge as an autonomous subject to proclaim them, Brazil experienced significant delays in adopting legal mechanisms to prevent these problems. Another factor is the restricted perspective of seeing the patient as a consumer, which strongly permeates human relations in the context of health care in Brazil. With a view to overcoming this delay, it is urgent that Brazil, in addition to adopting specific legislation, establishes the patient ombudsman as the main instrument, already globally accepted, to defend and guarantee the rights of the patient.

As seen in this article, there are several models that can be adopted. However, two characteristics are essential for all: focus on patients' rights and the investigation of their claims. In this way, the patient ombudsman differs from other health care ombudsmen who already exist in Brazil, especially by standing up as an advocate for patients' rights and assuming a unique role in preventing and responding to conflicts. In addition, patient ombudsmen are directly committed to the quality of care and patient safety by incorporating respect for their rights as a key factor in preventing and repairing adversity.

Therefore, we recommend a patient ombudsman model that takes into account the experiences of other countries, as well as the complexity and peculiarities of the Brazilian health system. To conclude, it is imperative that the Brazilian society mobilizes to take part in actions in

favour of patients' rights, an inexorable condition of any person, because the necessary changes will only occur if we broaden the perception that we

must break with blatant asymmetries of power in the area of health care, giving voice and autonomy to patients.

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