

Code of rights and obligations of hospitalized patients within the Brazilian National Health System (SUS): the daily hospital routine under discussion

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ABSTRACT

Patients' rights constitute a mechanism for change in care and management within the Brazilian National Health System (SUS). The aim of this study was to present roundtable discussions concerning the rights and obligations of SUS patients within the hospital environment. This is a descriptive, exploratory study, conducted at two hospitals in Fortaleza, Ceará. Three roundtable discussions were held at each institution, involving 40 staff members from various professions and sectors. The debate was centered on the text of the Code of Rights and Obligations of SUS Patients in Ceará. The discourses were analyzed according to the content analysis method of Lawrence Bardin. Analysis led to the perception that consolidated norms made it difficult to put the rights into practice and the roundtable discussions broadened this critical view, promoting further insight. This was shown to be an important educational instrument for citizens' rights and for humanization of the healthcare process.

Keywords: Patients' rights. Humanization of healthcare attendance. Health education.

Introduction

Consolidation of the founding principals of the Brazilian National Health System (*Sistema Único de Saúde*, SUS): universality, integrality, equity and social participation, as defined in the Constitution of 1988, faces important challenges in the practice of healthcare. The characteristics of social inequity and inequality, deeply rooted in Brazilian culture (Brasil, 2006a), the paradigm of healthcare focused on the biological body (Luz, 2004; Capra, 1996) and the characteristics of work and services management, namely bureaucratic, authoritarian, techno-healthcare and disorganized as a healthcare network (Brasil, 2007), provoke chronic dissatisfaction that is frequently exacerbated in both workers and users and places the social and political legitimacy of the SUS at risk (Feuerwerker, 2005).

It is known that although constitutional guarantees and the consecration of universal human rights exist in Brazil, there is an expressive distance between the law as written and the daily routine of health services (Gomes & Fraga, 2001). In a study conducted regarding the perception of hospitalized clients concerning their rights and obligations, observation revealed widespread lack of knowledge and apprehension in exteriorizing feelings for fear of reprisals by staff members. It also highlighted the importance of strategies involving health professionals to recuperate citizenship and respect for patients' rights (Velooso & Spindola, 2005). Patients' rights are not outlined in a single legal code (Timi, 2005), rather numerous documents guarantee the dignity of the individual requiring healthcare: the Brazilian Constitution, the Brazilian Civil Code, the Brazilian Penal Code, the Consumer Protection Code, the Child and Adolescent Statute, the Elderly Statute, the Health Plan Law and National Agency for Supplementary Health norms, professional ethical codes, Federal Medicine Council resolutions, international declarations of principals, norms for research on humans, Ministry of Health norms and diverse legislation and jurisprudence. In 1999, the Ministry of Health published a code of users' rights and, seven years later, the Code of the Rights of Healthcare Users (*Carta dos Direitos dos Usuários da Saúde*, Brasil, 2006b).

An important condition of the full exercise of citizenship is that patients are aware of their rights and obligations, thereby acting as a means of questioning the feasibility of the same (Gauderer, 1998). As these rights are assumed and equilibrated with the obligations assumed by the patients and their relatives, greater social control and collective participation in healthcare actions and management processes become easier. These values of autonomy and co-responsibility integrate the proposal of the humanization of healthcare of the Ministry of Health, understood as the valorization of the different subjects implicated in the production of healthcare - users, workers and managers (Brasil, 2006c) - and the protagonism in the decisions (Campos, 2005).

Aimed at furthering the political participation and critical vision of patients and concerned with autonomy and citizens rights, the Code of Rights of Healthcare Users is one of the mechanisms of the National Policy for Humanization and Management in Healthcare (*Política Nacional de*

Humanização da Atenção e da Gestão em Saúde, PNH) of the Ministry of Health. The understanding is that humanized, receptive and resolute attendance for all SUS users must be guaranteed (Barros & Passos, 2005). Despite several advances, including the rights recognized by the Federal Constitution and the regulation of the SUS, strengthening the instances in defense of consumer rights, these are not sufficient to guarantee the legitimacy of the right to healthcare for all citizen users. Given that such rights are partially dependent on the administrative and political action of the State, which does not always assure measures to protect such rights, the society is forced to create democratic spaces to affirm the right to healthcare, particularly in societies as authoritarian and unequal as Brazilian society (Chauí, 2006). Education has proved to be a means of access to information and political consciousness towards a change in healthcare practices that offend human dignity.

Integrating the national movement for humanization in healthcare, in 2003, the State of Ceará launched the State Policy for Humanization and Management in Healthcare of Ceará (*Política Estadual de Humanização da Atenção e da Gestão em Saúde do Ceará*, PEH/CE) (Ceará, 2005a) and the Code of Patients' Rights: a code of the rights and obligations of the hospitalized person (Ceará, 2005b), inspired by the concepts of Jaime and Carla Pinsky in the introduction to the magnificent *History of Citizenship* (*História da Cidadania*, São Paulo, 2003) compiled by them:

Being a citizen is having the right to life, liberty, justice and equality under the law: briefly, it is having civil rights. It is also participating in the destiny of society, voting, being voted, having political rights. Civil and political rights do not assure democracy without social rights, such rights that guarantee participation of the individual in the collective wealth: education, work, a fair wage, health and healthcare, a tranquil old age. The exercise of citizenship is being vested with civil, political and social rights (Pinsky & Pinsky, 2003, p.8).

The text of the code emphasizes the term "person", thus avoiding the contentious distinction between patient, client and user, and the insertion of gender ideology. The present written discourse principally opts for the term "patient", due to its emergence in the routine of these health services and in the naturalness of the accompanying speeches. Thus, the creation of forms of propagation of humanization policies and, especially, the strengthening of the collective in the discussion of the rights of citizenship applied to everyday realities are relevant.

The Code of Rights and Obligations is the final phase of a story that requires telling. As Health Secretary in 1992, Governor Lúcio Alcântara had a similar Idea. A resolution establishing criteria and defining rights and obligations was even published in the *Diário Oficial*¹ (Ceará, 1992). When he assumed the State Government in 2003, he asked the then Health Secretary to rework the code, motivated by the policy of humanization in

¹ Official Government Diary, publicizing all federal and state announcements, including laws, new appointments, etc.

healthcare. Analysis of the text permitted an understanding that it presented very solid content, while mixing rights, obligations, principals, justifications and directives in a technically inadequate manner.

The principals, directives and the justification integrated the text of State Policy for Humanization and Management in Healthcare of Ceará and the composition of the Code objectively concentrated on the rights and obligations. Next, consultation of other relevant documents were aggregated: the Declaration of Lisbon (General Assembly of the World Medical Association, 1981), reviewed in Bali in 1995; the chapter on health in the Brazilian Constitution (Brasil, 1988); the Founding Document of the National Program of Humanization of Hospital Care (*Programa Nacional de Humanização da Assistência Hospitalar*, PNHAH) (Brasil, 2002); a Handbook of the Brazilian Bar Association, Ceará Sector (Ordem dos Advogados do Brasil, 2000); certain books and texts used for validation (Gomes et al., 2000; Sampaio, 2000).

It is known, however, that the initiative of government members offers safeguards, a facilitator of actions, but this political will is of no use if the workers that execute the job, those who are on the frontline of the daily battle, who are in direct contact with the clients, do not engage in the project, do not change their attitudes, do not believe in the law (Ceará, 2006).

At certain historical moments, a vanguard can achieve the approval of a law, but it can fall into a vacuum because the majority of the workers, in this case, the healthcare operatives, do not feel motivated by or even understand the law. Thus, besides the originality of the launch of the Patients' Rights document in the State of Ceará, the Code of the Rights and Obligations of the Hospitalized Person in the SUS (*Carta dos Direitos e Deveres da Pessoa Hospitalizada no SUS*, Ceará, 2005b), it is important to highlight the originality of the application of the method of roundtable discussions concerning these rights and obligations, aimed at including the same in the consciousness and daily routine of health workers. Given this context, the objective of this work was to present the roundtable discussions concerning the rights and obligations of the SUS users in the hospital environment.

Methodology

This descriptive, exploratory research is based on the principals of the Training in Health and Work Program (*Programa de Formação em Saúde e Trabalho*, PFST) of the PNH, which articulates network training and research-intervention, aimed at dialogue-confrontation between scientific knowledge and workers experiences: nucleation of workers, circulation of concepts that permit understanding of the complexity of patients' rights; knowledge production and problematization the modes of management in course to alter the practices of disrespect of patients' rights; stimulus for collective projects and plans in defense of human dignity; strengthening of intersectorial and multiprofessional work that elicit understanding/transformation of the reality of daily practices, amplifying the normative capacity of health workers (Barros, Mori & Bastos, 2006).

Considering its characteristics of encouraging inclusion, participation, a democratic space of learning and informality, we choose the roundtable discussion as a pedagogical strategy for the methodological route, with the intention of disseminating the Code among the workers, who would later become multipliers in subsequent roundtables, while feeling completely at ease in the hospital environment. This is because the discussion format demands that each participant perceives the other, in order to congregate and incorporate dynamic and critical forms of reflection regarding their own practices.

Implementation of the roundtables occurred from April to June 2005, in two hospitals, one public and the other private, located in Fortaleza, State of Ceará, Brazil. Three interdisciplinary, intersectorial roundtable discussions were promoted in each of the two hospitals, consisting of 40 health workers in the following composition: doctors, social workers, nurses, administrative clerks, nursing assistants/technicians, pharmacists, engineers, general services workers, physiotherapists, psychologists, nutritionists and administrators. A number of these professionals exerted the functions of heads, directors and auditors or were members of the Humanization Working Group (*Grupo de Trabalho de Humanização*, GTH). The roundtable of one of the hospitals also counted on the presence of a representative from an organization of people living with HIV/AIDS. The participation of health professionals was prioritized due to the necessity to discuss and reflect with them new attitudes and possibilities for the dissemination of patients' rights in hospitals. Service users were to be included in subsequent roundtable discussions, facilitated by the newly trained multipliers.

Thus, practicing the Code of Rights in the daily routine of the hospitals was initiated. What awareness do health workers have concerning the rights of hospitalized patients? What attitudes do the workers need to change in themselves to guarantee the practice of these rights? What conditions do health managers need to provide to guarantee the practice of these rights? These were questions put forward in the workers roundtables and within the discussion circles.

Those who conduct the process are seen as facilitators, participants in a dialogue based on the personal experience and knowledge of each member, promoting problematization in search of information for reflection and action based on informed discernment. The acts of teaching and learning are an inseparable unit (Freire, 2004), permitting two-way transit and the sharing of knowledge and practices. For the discussion circles conducted, 150 minutes duration was registered. The participations were recorded for transcription, with the permission of the groups. The material of these transcriptions was systematized into a document for to the Health Secretary of the State of Ceará (*Secretaria da Saúde do Estado do Ceará*, SESA/CE) (Ceará, 2006) and is the basis of the present article. The results of the transcripts were organized according to the Content Analysis technique of Bardin (2002). The principals of National Health Council Resolution 196/96, which regulates research on humans, were followed (Brasil, 2001).

The project was submitted to and approved by the Ethics in Research Committee of Ceará State University, under protocol no. 04185929-4.

Development of the experience

State policy on humanization and patients' rights

The *PNHAH* was instituted in 2000, focusing on hospitals and the creation of the *GTH*. This process lasted three years and evolved in stages, with the State of Ceará conducting a pilot study at the Dr. César Cals General Hospital (*Hospital Geral Dr. César Cals*, HGCC), followed by an initial phase involving six hospitals. The second stage, planned for the end of 2002 and involving 30 hospitals, was truncated due to the election process for President of the Republic and State Governor.

At the onset of the first Lula government, the Ministry of Health submitted the *PNHAH* to a major revision and created the National Policy for Humanization and Management in Healthcare (*Política Nacional de Humanização da Atenção e da Gestão em Saúde*, PNH). The focus on hospitals evolved towards the primary healthcare network; the fulcrum on attendance spread to management-integrated healthcare and the vertical logic of a program grew into the transverse logic of policy. The challenge was amplified: emergency services, Intensive Care Units (ICUs), family healthcare, workers healthcare, healthcare for indigenous groups and mental health. It was not possible to abandon the hospitals and many of the *PNHAH* techniques, such as the *GTH* and the code of rights, were continued. The largest task was involving the municipalities of the capital cities and the health macroregions in the general effort of humanizing healthcare, above all in primary attendance. The Health Secretary of the State of Ceará decided that debating the Code of Rights and implementing the *GTH* would advance the work of the humanization of healthcare in hospitals.

The *GTH* of the Waldemar de Alcântara General Hospital (*Hospital Geral Waldemar de Alcântara*, HGWA) and the São José Hospital (HSJ) chose to be candidates to advance the discussion of the Code of Rights. The *PNH* consultant for the States of Ceará, Piauí and Maranhão and the Board of the State Commission for the Humanization of Healthcare and Management of Ceará were responsible for the mediation of the roundtable discussions, such that the experience and knowledge remained with the workers to facilitate multiplication.

Roundtable discussions as a pedagogical strategy

Roundtable discussions are an educative and communicative strategy, whose aim is the satisfaction of the basic needs of learning, understanding and empowerment. In the present essay, this technique was based on the proposition developed in the works of Simonetti, Adrião and Cavasin (2007, p.247), for whom “it is a space destined for dialogue, communication and the exchange of information [...] the people have an opportunity to acquire the capacity for discernment in a way that provokes a change in behavior and greater autonomy”. The principal goal is to permit the free expression of doubts, experiences and lived events.

The proposal was also based on the “Wheel Method” (*Método da Roda*), described by Campos (2000, p.68), the idea of which “considers the constitution of the Subject and the Collectives as a function of Planes situated between their internal world and its circumstances, the external world”, and on the thinking of Freire (2004, p.23), imbued by the notion that “those who teach learn while they teach and those who learn teach while they learn”

In the context of the study, rational and affective formulation of the rights and obligations of the hospital patient were applied by the members of the community of hospital workers, through active and effective participation. Regarding the quality of the pedagogical strategy, it proved capable of promoting reflection, the sharing of lived experiences and practical questions (Simonetti, Adrião & Cavasin, 2007).

Logic based on respect of the knowledge and experiences of the participants was centered on the valorization of the subject and the conversation, proportioning an exchange of ideas between the workers, so that everyone could incorporate the reasons and theories behind each right or obligation. The strategy was supported by the recognition of values and previous learning, which served as the basis for the constitution of new learning and of decision-making towards accommodating the existing reality to the rights of the hospitalized patient.

Discussion of the Code was based on the notion that each article was based on a theory. Reflection involved what Right entails, what the nature of the Right is and the different aspects of the Right. Following this, understanding was sought concerning the context of the Right, how it caused an impact on the service and, finally, problematization concerning the workers’ attitudes and the conditions the hospital should offer to make this Right a reality. Each article of the Code referred to six thematic orders: one technical, legal, psychological and anthropological; another relational, concerning the interfaces of the articles and of one right in relation to another; and, lastly, a third, political, emphasizing the effects on the practice of the worker. Some of these problematizations are rooted in working and living conditions, others in personal attitudes, which are the responsibility that the worker is required to develop. Information itself is not enough to change someone’s way of acting; transforming attitudes is a more delicate process. The code consists of 35 rights and 10 obligations, among which the discussion of articles 5 and 13 are highlighted as examples in this essay.

Analytical results: the workers’ voice

Health service norms and repetitive protocols used for years, with no justifiable function in the present, were questioned by the workers. The possibility of reinventing these norms, making work inventive, was discussed. Foucault (1999) affirmed that power only exists when there is resistance; since, initially, it subverts, reverses its position and escapes controls, making new forms of life and work possible. This workers’ perspective of shaking up that which had become routine permitted a rethink on the possibilities of concrete changes designed to guarantee patients’

rights, supported by the principal aspects elicited by the interdisciplinary debate.

According to Campos (2000), it is necessary to consider a dialectic tension between external control and the subjects' autonomy, since humans are immersed in history and society, though not divested of subjectivity and the capacity to maintain a position in the face of challenges to their conjuncture. An example of a collectively formulated text is highlighted in article five, which deals with the right of the patient to be identified by their name and surname. A female worker opens the debate:

This is a clear issue for me, but I don't know how to explain it. I see, over in Pediatrics, people calling all the mothers "mummy" all the time. For me, this has become so pejorative, it doesn't sound right. I don't know why, but it bothers me deeply. The diminutive can be affectionate on many occasions, but in this case it seems to be infantilizing. (Female hospital worker)

Following this, the facilitators comment: "mummy" is a generic form, it refers to an abstract category. There is early motherhood for girls who give birth at 12 years of age; delayed motherhood for women who give birth at 45; women who become pregnant in a stable, loving relationship; and women who are alone by choice or abandonment; women who are healthy or who have an associated disease; women who are poor or rich; moreover, there is the individuality of each subject. It seems, however, that it is much easier to use "mummy" than to ask for and learn the woman's name, to create a bond. You also need to include the accompanying father. Two other professionals expose their dilemmas and the need to modify this attitude: It's true. Men are hanging around the nursery. What are you going to do? Are you going to call the father "mummy"? They're not your mother, or father, or brother, or sister, or aunt; they are people that have names. The presence of the companion and the husband forces us to change much of our behavior. (Male hospital worker)

The patient is also called "baby": "Come here my baby"; or even rudely, "Hey, you there". Sometimes you find a nickname that the person likes: "check out Pele", "check out Lula", but others the person hates. You can't refer to someone as that "viadinho"² or "blacky" or "blondy"; none of these terms should be used. This kind of treatment can even create a form of bonding, but its negative, prejudice, disrespectful. There are people that think that the way to be nice is to include others as family members and begin calling everyone "uncle" or "aunty"³. (Male hospital worker)

Centered on the discussions, the facilitators return to the dialogue with a new explanation: what we need to do is ask the person their name and how they like to be addressed. Thus, the relationship should obey the reference given by the person themselves.

According to Fortes (2004), in many everyday situations, health professionals assume, in the name of "doing good", paternalistic and

² Roughly translates as *sweet gay man*, used as a tease or a nickname, though often used pejoratively.

³ A common informal Brazilian form of addressing older people whose name you do not know, rather than the formal use of Sir (*Senhor*) or Madam (*Senhora*).

authoritarian attitudes that they are unaware of, contrary to the autonomous wishes of citizens under their care and in violation of their rights.

Sharing in the roundtable can also be verified in the discussion involving article 13, which concerns the right to protect against bodily exposure and shame, guaranteeing the performance of exams in environments that preserve the patient's modesty. One worker in the area of administration and a nurse highlight the importance, to the patient, of being careful with personal intimacy:

We conducted a survey of user satisfaction and we had a significant percentage of dissatisfaction. We opened up the question and discovered this: "preserving personal intimacy". It was a problem of the hospital gown, without the use of underwear and open down the back, showing the buttocks when the patient walks. (Male hospital worker)

We had a patient who always had one breast exposed, because the clothes provided were a much smaller size than she was. She complained, but no one took care of it..., saying that there weren't enough gowns. Once I found a young lady consulting with the midwife, but without the protective screen. There was a lack of screens. It is very common to see people in the UCI with their bodies exposed, half naked, using those electrodes, those wires and no curtain, due to the heat. I call the nursing assistants and demand action: "check that out... let's be careful... let's protect them". (Female hospital worker)

The facilitators explain, eliciting the theme exposed by the workers: there is always a way to achieve this without high technology or high cost. It requires mobilizing sensitivity to perceive and creativity aimed at resolving the issue. It is very interesting to reflect on how we would feel in a similar situation, performing role-playing or mirroring games, techniques that psychodrama, for example, offers us to experience alterity. The question regarding the gowns brings up the compromise of management to create conditions that respect patient intimacy.

However, besides the questions of management and relationships, the increase in humanizing actions to better achieve these objectives should consider the principal of humanity, according to which humankind becomes the center of ethical action and not just the means of satisfying the interests of the social forces acting in healthcare attendance (Fortes, 2004). Within this framework, humanization and patients' rights should be at the core of health policies and programs (Vaitsman & Andrade, 2005).

Another theme mentioned by the professionals was how to educate the patient and their relatives concerning rights and obligations, with a clear notion that this social function also involves popular participation: "How do we also educate our patients concerning their rights? I think that it is more delicate than informing the professional. It is a great challenge that we are going to face throughout the process" (Male hospital worker). It also demonstrates the acquisition of knowledge of the professional concerning the importance of patients' rights. The reply to this question is broached by another professional, who said:

The basic question is the pedagogy of the encounter. Each time a professional explains something, this is education concerning rights. It's

within the daily routine that professionals can do this, if they have incorporated the attitude. Since every act of hygiene implies a dimension of education. Publicizing through the media, collectively informing patients, asking the *PSFT* to form groups in the community explaining the existence of the Code of Rights and Obligations, but the everyday example is needed, the example in practice. (Male hospital worker)

The facilitators discuss the importance of the role of the professional as educator in hygiene practice: in every moment that health professionals are relating with patients, they are teaching and learning. And, the majority of the time, they are teaching badly by allowing the patients to invent knowledge out of their silences. It is fundamental, therefore, that this educative work extends to patients, aimed at acquiring knowledge regarding inequality and the violation of their rights, strengthening social control and the fight against social inequities and the disrespect of human rights.

For the participants, concerning the experience of the collective encounter, the principal aspect highlighted was that the roundtable permitted them “to be aware of the living experience of the health professional”. In a context marked by urgency and the need for rational and instrumental decisions, in rare moments, professionals are led to reflect on their daily habits, which heighten the capacity to share common dilemmas, recovering the sense of group.

The roundtables were considered an “awakening”, “a discussion that amplifies our vision”, since they promoted “deep reflection”, permitting “recuperation of the person hidden inside the pathology”. As a consequence of participating in the roundtable discussions, one participant reported that “the people had the honor of participating and growing, a lot, since the roundtable provided a very good foundation for everyone”.

Final considerations

Amplifying awareness of users’ rights in the practice of services requires an educative process involving managers, workers and users. This is because the constitutional guarantees and legal codes are not sufficient to fulfill these rights in practice.

The proposal of the discussion of the Code of Patients’ Rights in roundtable discussions, aimed at understanding the history, the motives for the textual elaboration and evaluating the impact of the device, that is, what each hospital needs to do to fulfill these guarantees in terms of the conditions of functioning and attitude of the professionals, proved to be a promising route to provoke changes in the healthcare environment. Sharing experiences permitted greater internalization of the bridge created between discourse and reality.

The challenge of forming multipliers in patients’ rights is an imperative in the daily routine, given that humanized healthcare and health management will only be achieved by the dignity acquired and the consideration promoted in the relationship between all the agents of the public scene.

In the roundtable discussions, the Code was revealed as an important instrument for evaluating the state of humanization of hospital care and the

education of citizenship of the workers. It helped reflect on the relationships and conditions of functioning of such services, providing means for instigating change. The roundtable discussions promoted “groupality” stimulated by the force of the collective, which potentializes not solitary, but solidary thinking as a new way of promoting healthcare through the solicitation of citizen and humanitarian ethics.

Collaborators

Annatália Meneses de Amorim Gomes elaborated the research, conducted the roundtable discussions, constructed and revised the article and prepared it for consideration by the journal. José Jackson Coelho Sampaio elaborated the research, conducted the roundtable discussions, constructed and revised the article. Maria das Graças Barreto de Carvalho participated in roundtable discussions, debated aspects of the text and contributed to data analysis. Marilyn Kay Nations participated in roundtable discussions and contributed to the organization, analysis and discussion of the results. Maria Socorro Costa Feitosa Alves constructed the article, collaborated in the analysis and discussion of the data and participated in the revision process.

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