

Patient's autonomy: a situational analysis of an emergency unit

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Abstract

The emergency units constitute an important report of observed conditions of the health system, functioning as an information source for surveillance actions. The physician-patient relationship, based on humanitarian, ethical and legal grounds, ensure a correct diagnosis and treatment. The informed consent is a prerequisite of this relationship, the practical expression of, relating to the autonomy of patients. Autonomy includes the ability to self-determination, think and act independently. The disease threatens the integrity -harming of human choice and decision making, conditions which physicians should encourage patient's participation of the throughout the process. The objective is to discuss medical procedures with patients undergoing emergency surgeries under the ethical perspective. Descriptive, qualitative research, conducted through individual semi-structured interviews, with the patient who had undergone traditional cholecystectomy in the period from July to November 2011, at the clinic of Trauma and Emergency Surgery of a university hospital. It was concluded that the physician-patient relationship in the sector of hospital emergency department reference has the characteristic of anonymity. At the time of emergency, the patient is faced with the unknown doctor and hospital.

key words: personal autonomy. bioethics. epidemiology, descriptive. emergency medicine.

Resumo

Autonomia do paciente: análise situacional de uma unidade de urgência

As unidades de urgência constituem um observatório das condições do sistema de saúde, funcionando como fonte de informação para as ações de vigilância. A relação médico-paciente, calcada em bases humanitárias, éticas e legais, propicia o correto diagnóstico e tratamento. O consentimento informado é uma das condições indispensáveis dessa relação, a expressão prática do respeito à autonomia dos pacientes, bem como discutir as condutas éticas com pacientes submetidos aos procedimentos cirúrgicos de urgência relativa. O presente trabalho resulta de pesquisa qualitativa-descritiva, realizada mediante entrevistas individuais, semiestruturada, com pacientes submetido à colecistectomia tradicional, no período de junho a novembro de 2011. Concluiu-se que a relação médico-paciente no setor de urgências tem como característica o anonimato e que os pacientes se deparam com o desconhecido, em relação ao diagnóstico, médico e hospital, o que algumas vezes lhes provoca temor e dificulta a relação.

Palavras-chave: Autonomia pessoal. Bioética. Epidemiologia descritiva. Medicina de emergência.

Resumen

La autonomía del paciente: un análisis de una unidad de urgencia

Las unidades de emergencia constituyen un condiciones observadas en el sistema de salud, que funciona como una fuente de información para las acciones de vigilancia. La relación médico-paciente, basada en razones humanitarias, éticas y legales, asegurar un correcto diagnóstico y tratamiento. El consentimiento informado es un requisito indispensable de esta relación, la expresión práctica de la relación con la autonomía de los pacientes. Este artículo objetiva desmaldecir los procedimientos médicos, con los pacientes sometidos a cirugías de emergencia en virtud de la perspectiva ética. Fue un estudio descriptivo, la investigación cualitativa, llevada a cabo a través de entrevistas individuales, semi-estructurada, con el paciente que se habían sometido a una colecistectomía tradicional en el período de julio a noviembre de 2011, en la clínica de Trauma y Cirugía de Urgencias de un hospital universitario. Se concluyó que la relación médico-paciente en el sector de emergencias de un hospital de referencia del departamento tiene la característica de guardar el anonimato. En el momento de emergencia, el paciente se enfrenta al desconocido doctor y el hospital.

Palabras-clave: Autonomía personal. Bioética. Epidemiología descriptiva. Medicina de emergencia.

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Due to low investments in health promotion units, emergency units became, inadvertently, a kind of "laboratory" to assess health conditions of population and health system's work. Since they receive the majority of patients with unusual health damages, they are characterized as a continued source of information for health surveillance actions.

The characteristics and frequency of problems that are taken to emergency units may be "read" almost as a health map, which shows the reproduction of old problems and points to failures in integrality of care. It allows to infer, particularly, the scarcity of educational activities to prevent and protect from known risks and aggressor agents, as well as structural deficiencies that make difficult people's health recovery and rehabilitation ¹.

Due to its own specificity, urgency care ends up, often, not meeting basic ethical precepts in physician-patient relationship, mainly those relate to information to patient on diagnosis, therapeutics, and prognosis, and the indispensable clarification for signing the consent to carry out exams and treatment, particularly the invasive. Under such point of view, this paper presents and discusses aspects of medical team behavior that harm these ethical features in dealing with users, with emphasis in autonomy and the free and clarified consent term of patients undergoing an emergency surgical procedure.

Urgency and information

The Federal Council of Medicine (CFM) Resolution 1,451 ² defines as urgency the *occurrence of unpredicted health damage with or without potential risk to life, whose carrier needs immediate medical care* ³. As this situation encompasses a broad range of relative and absolute situations that must be solved with maximum readiness, it tends, often, to inhibit attitudes such as reception, intimacy and naturality, which takes back humanization in care, should be materialized in a context of technical and specialized efficiency ⁴.

Since in emergency situations, mainly in public hospitals, it is not possible to choose the physician who will provide care as the system consists, in its majority, of on-duty shifts, with different physicians in each shift, *users become medical records numbers and clinical staff into technicians, with the binomial involved in insecure and defensive attitudes environment* ⁵ that affects everyone. This adverse situation for both groups, professionals and users, provides that indispensable ethical features for a good phy-

sician-patient relationship, such as respect for autonomy stated in the free and clarified consent term (FCCT) are often forgotten, mostly in cases of patients who underwent emergency surgical procedure.

Thus, getting a FCCT is not frequent in both relative and absolute urgencies, either by the situation itself or by total lack of knowledge of actors involved in the process. However, getting a patient's consent is a physician's duty, set forth in Article 22, Chapter 4th of the Medical Code of Ethics (MCE) that interdicts physicians of *not obtaining a consent from patient or from his/her legal representative after clarification of the procedure to be undertaken, except in case of eminent risk of death* ³. The clarified consent attributes to patient the duty of participating in any decision on his/her treatment, that is, to decide on everything that might affect his/her psych-physical integrity. He must mandatorily be informed by the assisting physician of treatment's risks, benefits and alternatives, been recognized as capable of choosing the Best for him/herself, under equality of rights and opportunities point of view.

Pessini *et al.* ⁶ state, reflecting on current MCE and terminality of life, that *it represents an innovative opening since it constitutes a resulting view from different professionals, inclusively civil society, in dealing with knowledge, updates, and new competences with the scope of health* ⁶. They highlight, in MCE larger context, the *emergence of physician's identity as patient's advisor and partner, from a not only biological view, but basically humanistic*. They warn, still, *to this end that it will be necessary for physician be prepared to assist the patient, seeing him/her as integral being endowed with feelings, expectations, and with the right to decision making that ensure him/her dignity in life* ⁶.

The *clarified consent* is expression of respect for people and, incredibly, it only begun to be discussed and regulated in 1940s; The incorporation of this bioethical element in clinical practice and in medical deontological code took a little longer and, even now, many professionals still do not consider this need, keeping a paternalistic behavior ⁷ in their daily. Nevertheless, the clarified consent is indispensable instrument for good medical practice, and not just a legal instrument, but patients' moral and ethical right that generates obligations to physicians. And it is impossible to speak on clarified consent without approaching the principle of willingness autonomy in patient's behavior, being the sole agent of his/hers own acts and will ^{8,9}.

Santos *et al.* state that *autonomy includes the capability for self-determination, in order to resist*

social pressure and to act more independently. The relationship among family members, in home caring during a disease process, is maintained, there is autonomy in occupying its space, that is, each occupying a place in the family structure. During internship, authors have defined roles, some are ill, others companions and the health professionals are the controllers, but all under rules set to ensure the good work of the system, what does not reflect always the best for the sick individual. Study with in-hospital patients has shown that autonomy was less developed and dangerously exposed to others' decisions¹⁰. The physician-patient relationship, set under humanitarian, ethical, and legal bases, ensure the Best inter-personal relationship and it favor the correct diagnosis and therapeutics⁵. We consider that these features will be achieved only through correct and reliable information to the patient, which includes the precise explanation on diagnosis, treatment, and prognostics, shown, among other aspects, through patient's autonomous signature of FCCT.

Method

The transversal study, of the qualitative-descriptive type¹¹⁻¹⁴, adopted the social representations theory (SRT)¹⁵, described by Moscovici as methodological reference, *because it presents great adherence to objects of studies in health areas by targeting subjective aspects that pervades problems inherent to the area*¹⁶. In order to know and describe the meanings about physician's considerations related to the patient and to evaluate his attitude concerning urgencies in health, under STR referral, the chosen method was the analysis of Discourse of the Collective Subject (DCS), because it allows approximation to the phenomenon under study¹⁷.

After FCCT signing, individual, semi-structured interviews were undertaken with 43 patients, which were recorded, transcribed, and analyzed under strictly set methodological criteria. It was used, in order to calculate the sample, the sampling closing process by theoretical saturation, *defined operationally as suspension of inclusion of new participants when obtained data began to present, in researcher's evaluation, a certain redundancy or repetition, and to maintain data collection is not considered as relevant*¹⁸⁻²⁰.

Data collection was undertaken from June to November 2011 at Padre Albino's University Hospital, in the city of Catanduva/SP. Study participants

were patients undergoing relative urgency surgical procedure, traditional cholecystectomy, because it represents, in researchers' view, a routine procedure undertaken in every shift at the surgery clinic and, still, because it provides enough time for a clinical evaluation (pre-surgical), FCCT guidance and collection. Interviews were carried out between the fifth and seventh day after surgery, during patient return to the urgency and trauma surgery unit, at the Emílio Carlos University Hospital in the same city.

Interviews investigated perceptions presented on the physician-patient relationship and its inherent bioethical conflicts. Ethical questioning in this paper were designed in accordance to MCE in force. In order to analyze and present the outcomes, it was used interviewee's own speech (P), written in the first person singular, comprising key-expression (ECH) that had the same central ideas (IC), and anchoring (AC), strictly complying to the following stages order: 1) answers were heard several times and only after the Best understanding of the general Idea of the discourse, they were transcribed literally; 2) overall reading of each interviewees' responses, followed by separate reading of all responses for analyzed questioning; 3^a) transcription of responses for each questioning, in increased numerical order, marking ECHs in italics and indicating the ICs that represented the description of the ECHs; 4) individual transcription of each central idea, with its respective ECHs; 5) extraction the topic of each question, grouping their respective ICs. Finally, separate DSC construction for each central Idea with its respective ECHs was carried out.

Research subjects were grouped, after tabulation by DSC and ECH, as database using the software Epi-info® release 3.5.1.

Results and discussion

Profile

Os surveyed patients, 75% were female, with average age of 50.8 yrs. old for women and 49 for men. The schooling level with highest prevalence was complete basic education (54.3%) and family income of 1 to 2 minimum wages (63.6%). Concerning analyzed question, it was chosen to present the results and associated discussion, as this type of narrative favors the description of qualitative works²¹. In order to facilitate reader's understanding, the text was subdivided in accordance with analyzed question, which are presented next.

“When arriving at the hospital, in the urgency unit, how were you informed by the medical team about your disease?”

Analysis of common discourse presented two central ideas: “I was well informed” (90.7%) and “I was not well informed” (9.3%). In spite of near absolute majority consider to be well informed, singular elements in the discourse provide room for different interpretations. According to Crepaldi, *even with the intense search for a humanized medicine, practices continue submitting patients and their family member to situations of embarrassment and lack of consideration, been forgotten that primary objective of the hospital function should be to rescue citizens' health and dignity. The patient of his/her family are not always informed on what will take place in the hospital, without mentioning that, in many instances, the patient is not consulted if he/she accepts or not to undergo certain procedures, or that his/her family is able to decide for him/her when he/she is unable to do it*²², which can be seen the following depositions: “They took me inside and they did not say anything” (P 26); “They did not say anything correctly, everything was too fast” (P 29); “The said only that a complication appeared, when I realized it I was undergoing a surgery” (P 35).

The physician-patient contact is a highly specific relationship due to presence or possibility of a disease provides it of features that are hardly found in any other human relationship. At every moment, human being's unpredictability, science imperfections, his own limitation in face of the reality of pain and questioning on death are place in front of the physician. This anguish is repeated in each contact with a new patient, and it not explicitly evidenced because the physician, by repeatedly experiencing it, seeks to design mechanisms to face it, although expected result is not always achieved²³.

Serious diseases place under risk human's own integrity. According to Drane and Pessini²⁴, *the disease is the foe of acting, of liberty, and of self-determination and, in a serious disease, a broad harm is suffered, followed by a devastating loss of power of remedy for the harm suffered. Hence, if the choice, the initiative, the decision-making, and responsibility are influenced by the patient's illness, the physician has the duty to promote and stimulate patient's participation in diagnostics and therapeutics decisions, and to foster patient's self-determination*²⁴.

Thus, one lives a paradox situation, as, on the one hand, we have the patient been deprived of his/her liberty of choice and self-determination and, on the other hand, the clinical staff, with the limitation

imposed by medicine's own nature. Both tend to develop defense mechanisms, generally harmful to physician-patient relations – which finishes by deteriorating human and professional relationships between the physician-patient (and family members) binomial.

“Was it offered to you (or your family member) a consent term with diagnosis, prognosis and treatment possibilities?”

Of total interviewees, 72.1% alleged not having knowledge of any consent term. However, hospital standards defined that every patient admitted to service mandatorily sign a FCCT, along with hospital internship papers. Thus, this discrepant outcome provides room to interesting discussion on understanding, by patients, of what they are signing. This conflict can be noticed in the following reports: “They ordered me to sign a paper, but they did not explain anything” (P 10); “I signed, but the way that I felt, I did not want to know anything” (P 15).

Information is, among the requirement to obtain a FCCT, the most important, reason by which it should be clear, objective, and in a language compatible to patient's comprehension. Ignorance is the normality regarding technical terms, and the health professional should avoid using them. Silva²⁵ advises that *physicians should be punctual, choosing which information are important for patient's decision, and they should not attain more to benefits than to risks, under liability of responding for omission of relevant datum. The weighting of what language and amount of information to be provided, the patient's level of understanding should be considered, as well as the seriousness of the intervention to be undertaken. The main purpose of information is to supply the patient with basic element for his/her decision. It is worth highlighting the purpose of information for validity of consent, as the hypothesis of submission of patient to medical treatment for insufficiency of data explanation; the clarified consent will be invalid*²⁵.

Non-supply of needed information to the patient is understood as negligence, liable to be accountable, since *negligence means carelessness, non compliance to technical or even administrative standards*²⁶. However, we can notice in one single patient's report what should have been routine of service: “Yes, I read and signed it” (P 33). Torres²⁷ refers that, in recent work, the *good medical practice still is based in observing Hippocratic concepts – beneficence, non-maleficence, respect for life, confidentiality, and privacy – added by respect to*

patient's autonomy, his/her right to get all information and to participate more actively in his/her treatment. One may infer, from this, that only with patient's due clarification, by means of information provided by the physician, the physician-patient relationship can be strengthened, ensuring him/her autonomy, and that such aspects still are not sufficiently consolidated in urgency services practices.

“Were you informed on the surgical risks?”

Analysis of common discourse presented two central ideas: “Yes” (16.3%) and “No” (83.7%). According to Pereira ⁵, invasive and risky interventions are, often, ill-informed to patients or their family members, and the absence of appropriate environment for exchanging confidential information prevents greater closeness among both, what can be noticed in the expressions: “The physician said that there would not be any problem” (P 13); “They did not say anything to me, except if they said it to my wife” (P 27); “Only during the anesthesia, but then, I was there already” (P 29).

We can notice that Article 34, Chapter V of the Medical Code of Ethics prohibits the physician of not informing the patient about the diagnosis, prognosis, risks and treatment objectives, except when direct communication may cause him/her harm, and in this case, he should communicate to his/her legal representative ³. Therefore, non-information about the risks of a surgery is a disrespect to patient's autonomy and it goes against the governing legal norms. Every individual has the right to consent or refuse proposal with preventive, diagnosis or therapeutics feature that have the potential to affect his/her physical, psychic or social integrity, while it is the physician's obligation to provide this option to the patient ²⁷.

“Did you, at any time throughout your internship, suffered and kind of embarrassment?”

Pupulim and Sawada report that *in health care, violation of privacy of the individual may take place in varied ways and at different levels, such as of information, of personal and territorial space, of the body, in the psychological and moral realm. It is unarguable the merit of this, nevertheless, one questions which are the limits and standards for the professional's work, bearing in mind patient's rights, and to expose and touch the body, in addition to obtained information, is inherent to health care. It is interesting to point out the lack of specific laws targeted to privacy related to users' physical access to health systems. The codes of ethics foresee profes-*

sional's duty and patient's right to privacy, as well as the Brazilian Constitution and the Universal Declaration on Human Rights, but they are not explicit nor there is enforcement, seeming to be more Standards and recommendations, perhaps because the limit between the necessary and the excessive is subtle and difficult to be determined ²⁸. In this paper, 90.7% of patients denied any sort of embarrassment. However, 9.3% of interviewees complained about lack of information, bad nursing service and difficulties in dealing with little privacy and body exposure, reasons that have created discomfort: “I was only frightened with so many people in the room who I did not know” (P 10); “I was embarrassed in been dependent on other people and ashamed in wearing those hospital clothes” (P 16).

The study undertaken by Woogara noticed lack of privacy for body hygiene and wearing hospital clothes that always left the body naked, mainly the genitals, and it identified the need of control and the individual option to get it, observing that patients had little chance in choosing. It points out, still, that they accept the lack of privacy without protesting in order of not been tagged as unpopular and it comminates in less privacy because of priority for health team needs, and because they believe that care is more important than preserving their own identity ²⁹. Although some individual have manifested annoyance, others see nudity spontaneously, perhaps because it did not really matter to them; because the approach was suitable or, still, because they considered as inevitable, as it can be noticed in the remark: “It is here, there cannot be shame” (P 4). This kind of statement leads to believe that, given the absence of privacy for body hygiene, as well as lack of decency of hospital clothing, they are imposed to patients as inherent to the institutional dynamics, it seems that many of them do not question them for prioritizing treatment and health recovery.

Such considerations seem to point to the fact that many professionals are not aware that they must respect patients' privacy and dignity, taken as less relevant than care or treatment ²⁹. Respect for integrity certifies dignity and should be understood as right to individuality related to physical (modesty related to certain body parts) and psychological aspects (respect for values, opinions, and thoughts) of the individual ³⁰.

“What would you like to be improved concerning your autonomy and rights?”

Currently, patient's autonomy is a frequent topic, since the traditional paternalist model is not

accepted anymore, in which the physician decides, for his/her patient, what is the Best treatment³¹. A publication by the Regional Council of Medicine of the State of Paraíba states that *autonomy means self-government, self-determination of the individual in making decision related to his/her own life, health, physical-psychoic integrity, and social relations. It presumes the existence of options, freedom of choice and it requires that the individual is able to act according to deliberations made. Respect for self-determination is based in the principle of human dignity, accepting Kantian categorical imperative stating that the human being is an end in himself. Some variables contribute toward an individual to become autonomous, such as the biological, psychoic,, and social conditions. Current good medical practice continues to be based in enforcement of Hippocratic concepts of beneficence, non-maleficence, respect for life, confidentiality, and privacy, added by respect for patient's autonomy, his/her right in getting all information and participating in his/her treatment more actively*³².

Four central ideas (IC) were gotten in this paper referring to patients' view in face of their autonomy and rights: 1) "Nothing to be improved"; 2) "More information"; (3) "More agility in assistance" and 4) *adequacies in the nursing team*. The majority of interviewees (72.1%) did not present any proposal to improve compliance to their rights: "In my point of view, there is nothing to improve because I was well cared and they did not neglect me at any time" (P 4). However, in some cases, one realizes that acceptance of the preset context in detriment to personal autonomy arises, probably, due to low schooling of studied population, which implies in accentuated level of lack of knowledge about their rights. This fact is exemplarily illustrated in the speech that follows, in which the user of the Single Health System (SUS) states the gratuitousness of the service: "No need to improvement for me ... been free, it is fine" (P 6).

The principle of autonomy is not respected when there is lack of information to patient concerning the procedure that is intended to be undertaken, and the absence of the free and clarified consent term, granted voluntarily and specifically for each procedure. This lack of respect for autonomy may be identified in 16.3% of patients who expressed the desire for more explanation related to their disease: "I think that they (physicians) should explain things more so one would feel more safe" (P 17).

Autonomy was one of the most important bioethical conquest in the 20th Century and it leveraged the emergence of new conflicts in the

physician-patient relationship, which should be faced and reflect by both actors of this particular relationship³³. Respecting autonomy is acknowledging that it is up to patient deciding on his/her own fate, according to his/her world view, based on own beliefs, expectations and values – even when they diverged from those prevailing in society or advocated by physicians. Gondinho states that *patient's rights should get special attention. This is because physician is dealing with someone else's health. Using unsuited procedures, medical error, ill-guidance, among other adversities present in the relationship between physicians and patients may cause damage difficult of been repaired, often irreversible, for the physical and psychological health of people seeking for medical assistance aiming at healing diseases, physical and aesthetics enhancement or for just a simple medical visit*³⁴.

Final considerations

The physician-patient relationship in the emergency sector, particularly in public hospitals, has anonymity as characteristics. The physician and patient meet and, almost always reciprocally, they do not know the other's name. At a moment of medical urgency, anyone who does not have clinical knowledge is fearful about what is happening, It is under this adverse circumstance that the ill individual (generally) faces unknown physician and hospital, which contribute for his/her inferiority feelings, making the relationship and caring even more difficult.

Although the assistance time is scarce, either by emergency feature or by the logistics of service demands itself, nothing prevents physicians to use it with politeness and kindness³⁵. However, the data from this study, allows to inferring that communication practices still are a challenge for building social citizenship in Brazil. For Romano³⁶, *there still is a long path in this realm; the communication process of knowledge is as complex or greater than the process of knowledge invention*.

As practical outcome of this survey, there was sensitiveness of managers and technical staff, mainly from medical professionals involved with teaching at the Institution that was the background for data collection, considering both undergraduate and medical internship students and professors. As consequence of this study, the survey hospitals are, connected to the medical course at Padre Albino Integrated College, under Standards reformulation

and implementation processes, as well as adapting to the continuous and permanent educational routine for the entire clinical staff, acknowledging the need of humanization and correctly assistance to patients.

It worth highlighting, among these cheerful initiatives, the innovation of FCCT for the invasive medical procedures. From survey's data analysis, the generic and standardized consent terms will be abandoned, prepared in technical language, in which any relevant information for the patient is absent, and they will not be used in large scale as mere informative booklets or, in some case, "non-informative".

We stress still that this study presents limitation at internal validity level, since it was analyzed one a representative sample from one single clinics within a specific social and geographic context. However, studies show that this reality is similar or

worse in many other specializations and sectors of Brazilian hospitals³⁷. Concerning limitations at external level, foreign variables cannot be controlled in as much as the approached topic is influenced by subjective aspects such as culture, education, feeling, emotions, beliefs, and values – which influence interviewed patient's positioning. External validity is conditioned as well, since it is not possible to generalize places or sample except for those studied, only allowing for transferring finding to similar realities³⁸.

Anyway, it is worth adding as final reflection that survey's applicability to enhance services rendered by the Institution points toward progresses that can be achieved with the closeness of the relations between clinic and academia, particularge regarding promotion of ethics in health.

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Authors' participation in the article

Thaís Buraschi Sene and Mariana Lourenço Lino participated in study planning, data collection, statistical analysis, and final writing. Ricardo Alessandro Teixeira Gonsaga participated study planning and guidance, statistical analysis, and final writing. Eduardo Marques da Silva participated in study planning and final writing. Therezinha Soares Biscegli carried out data verification (internal validation) and final review of text. All authors read and approved this article.

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