

Modesto Leite Rolim-Neto,^{1,2} Alberto Olavo Advincula Reis,²
Sionara Melo Figueiredo de Carvalho,¹ Marcial Moreno Moreira,¹
Henrique Cesar Nascimento Ramalho-Filho,³ Nádia Nara Rolim Lima,³
Uilna Natércia Soares Feitosa,³ Maria de Fátima Bezerra de Alencar,³ Fernando Adami⁴

VULNERABILITY AND THE BIOETHICS THROUGH THE EXPERIENCES OF ILLNESS

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Summary: Background: Vulnerable people are relatively or absolutely incapable of protecting their own interests. Vulnerability is an anthropological attribute of human beings due to the simple fact of being alive. Brazilian society has long been established as a matter through the eyes of social scientists. In the name of it, the vulnerability in the doctor-patient context is now being a much-discussed issue. **Purpose:** This study aims to analyse the current studies regarding the insertion of vulnerability in the health issue, reflexively dealing with the ethical matters involved, as well as with the narratives' insertion in this process. **Methods:** This article is based on data extracted from Scientific Electronic Library Online (Scielo) and on secondary data from textbooks about vulnerability, ethics, physician-patient relationship and narratives. **Results and discussion:** Doctors are faced with dilemmas in clinical practice: moral, ethical, legal, social, religious and economic. On these occasions, question their own values. By listening carefully to the stories of patients, health professionals broaden their perspectives, organize and integrate complex situations, which assists in conducting these difficult situations. **Conclusion:** Reflect the concept of vulnerability raises (re) think health practices, particularly in bringing to light the social experience of illness and hospitalization of the patient.

Keywords: Vulnerability, Illness, Narratives, Depression.

INTRODUCTION

Ruth Macklin (1) in an article entitled “Bioethics, vulnerability and protection” posed the following question: what makes individuals, groups or countries vulnerable? According to the definition of the International Ethical Guidelines for Research, reviewed by the Council for International Organizations of Medical Sciences, vulnerable people are relatively or absolutely incapable of protecting their own interests (2). In fact, more formally, may have power, intelligence, education, resources and insufficient forces or other attributes necessary to protect their interests (1). Light of this definition, the main feature of vulnerability expressed by this guideline is “a limited capacity or freedom”, showing that specific groups could be considered vulnerable (1). In the words of Kottow (3), is an anthropological attribute of human beings due to the simple fact of being alive.

Being vulnerable, therefore, means to be susceptible to damage. Paraphrasing Zuben (4) the vulnerability can be understood as an subjective category, essential to understanding the human being, as it expresses the finitude of the human condition as a mortal. That is, recognizing the human vulnerability is the same as saying that he and subject to (pathos), sensitive to any action stemmed from another being or the world environment. For the author, also means that man is a being situated in a world significantly interacting with others and the environment. To understand man as a finite state means that its corporeality is not purely and simply unidentifiable to a mundane thing, objectifiable and manipulable. Thus, in the concrete sense and the vulnerable who can be reached for something in the physical, psychological, social or moral. It may be related to the idea of suffering.

1 Faculty of Medicine of Ceará Federal University — UFC, in Barbalha, CE, Brazil

2 Faculty of Public Health of University of São Paulo — USP, São Paulo, SP, Brazil

3 Suicidology Research Group — Barbalha, Brazil

4 Faculty of Medicine of ABC — São Paulo, Brazil

For a line very similar Nichiata et al. (5) defines vulnerability as: a) the degree to which a population is exposed to susceptibility or risk of damage caused by natural disasters; b) the relationship between the intensity and magnitude of harm resulting of a threat, adverse event or accident c) likelihood that a particular community or geographic area must be affected by a potential threat or risk of disaster, established. Mendosa and Kowarick (6, 7) point out that the assumption of the condition of social vulnerability, economic and civil a part of Brazilian society has long been established as a matter through the eyes of social scientists. In the name of it, the vulnerability in the doctor-patient context is now being a much-discussed issue. Sanchez and Bertolozzi (8) distinguish the importance of studying the concept of vulnerability as an invitation to renew health practices and social and historical practices, by working with different sectors of society and transdisciplinary. This allows you to rethink the practice of critical and dynamic way, to contribute to the pursuit of political, cultural, cognitive and technological impact on promoting epidemiological profiles. Mitchell (9) shows that it is important to point out that the vulnerability and autonomy, although formally separate, to be applied in bioethics, should be taken as partners, as a condition of the subject of joint action. According to Koerich, Costa and Machado (10), in Brazil, the 1988 Constitution states that health is everyone's right. Thus, every citizen has the right to health care when you need it, regardless of having or not a health plan. According to current studies (1, 5, 8), the issue of vulnerability and ethics has been important factors for implementation of public health, improving the connection between doctors and patients.

Roughly speaking, primary care includes the set of actions of individual or collective, located in primary care health systems and aimed at promoting health, disease prevention, treatment and rehabilitation. Zoboli and Fortes (11) indicate that with the implementation of the SUS (Unified Health System, which is Brazilian's public health system, that accounts for more than 180 million insured and was created in 1988 by Brazilian's Federal Constitution) as it represents a process of change in the practice of health care demands of professionals, managers and attitudinal and cultural changes, requiring an ethical twist. Thus, to meet the challenge of achieving them, it is necessary to deal with ethical issues experienced in health services, especially in primary care, which has been deprecated by the bioethical reflections.

The curious and bioethical reflections that are comprehensive and should always address all angles of the issues in focus, whether they are emerging characteristics, thus more exciting, they are more traditional,

hence more conservative (12). In other words, modern science breaks with the separation between episteme (theoretical knowledge) and *Tecnic* (applied knowledge) (13). The experiences in primary care in Brazil, have witnessed the subordination of the models to disease and medical intervention individual, organizational structures submerged in technical, placed and replaced in the service of ideology, virtually free of democratized discussions that could expand and commit themselves to the point of capturing the real needs of users and workers (14). To that end, fundamental relational technologies that enable the uptake of health needs, which is possible by qualified hearing, the link emanating from the meetings, which must contain symmetrical relations and not overbearing or that may hinder freedom, seeking the autonomy of individuals in the construction and choice of specific therapeutic project (15).

So do not hesitate to point out that the ethical problems encountered in primary care may differ from those identified in other spheres of service, namely (11): (A) health problems differ according to the level of actions and procedures offered; (B) ethical subjects, users, relatives and health professionals are also different. By the very condition of admission, hospital users have the ability to autonomous decisions compromised. Health professionals in primary care, usually aimed at longer-term goals from the full attention and not just solve a specific problem; (C) the scenario in each type of health service differs, and this is important in that ethical problems arise from the context in which they operate. In the basic health units, the meetings with the users are more frequent and less urgent situations. The emergency, the immediacy and drama of the situations experienced, for example, in emergency rooms or intensive care units make the ethical problems are more evident, stormy and heavy, while in basic health units, we present the more subtly, through often unnoticed; (D) the solutions to ethical problems similar may differ because, even if we observe the same ethical framework for addressing the subject and context are different, ie, the inputs of the decision making process are distinguished.

Without a shadow of doubt, the development of technologies, the complexity of the equipment, the difficulty in having the knowledge of their management and time required to acquire the skills of how to apply them correctly as necessary, set a distance between the doctor and his patient that will increase the more specialized training is the professional. Often hidden behind your equipment, the doctor presents the patient (12). Coa and Pettengill (16) show that in the context of the health team, the vulnerability is evidenced by the conflicts of the family with the team, marked by lack of dialogue, disrespect and being away from home for their role. As a result, the family alternates moments where

you cannot do anything with others in trying to recover their independence, and is therefore a dynamic and continuous movement which gives a transitoriness to the feeling of vulnerability through the experience of illness and hospitalization of the patient. Bertolozzi et al. (15) reported that in view of vulnerability, exposure to injuries resulting from health aspects of individual and collective contexts or conditions that produce increased susceptibility to injuries and death to both the ability and resources to fight them.

Therefore, for the interpretation of health-disease process, it is considered likely indicates that the risk and vulnerability is an indicator of inequality and social inequality. The vulnerability precedes risk and determines the different risks of becoming infected, get sick and die. Grossman, Cardoso and Poirier (17, 18) point out that the last two decades another aspect that is being valued by health professionals, patients and ethicists are the narratives and medical ethics. Although the disease is a biological phenomenon and material, the human response to this event is not biologically determined arithmetically or translatable.

The uniqueness of each case emerges in the act of narrating. To see it, the trader needs to be competent to follow the thread of the narrative of the patient, to make sense of their symbolic language, understand the meaning of the stories and imagine the disease by the patient's perspective, often contradictory. The way the patient talks of his illness, how the doctor is in words, who listens in clinical discussions, which moved the audience is feeling and thinking are profound ethical dimensions involved in health care of people.

This study aims to analyse the current studies regarding the insertion of vulnerability in the health issue, reflexively dealing with the ethical matters involved, as well as with the narratives' insertion in this process.

METHODS

Included in this study, analyzes based on primary data extracted from original publications contained in the database of the Scientific Electronic Library Online (SciELO) and extracted from secondary textbooks. There were no restrictions on language or type of article. We performed a manual selection of texts, through descriptors: vulnerability, ethics, physician-patient, narratives. Of these articles, we excluded those that addressed the different thematic purpose of this study. A total of 28 articles dating from the period 2002 to 2011 were selected.

RESULTS AND DISCUSSION

Sanchez and Bertolozzi (7) describe the model of vulnerability that connects the individual aspects, so-

cial and programmatic. They recognized social determination of disease and stands as an invitation to renew health practices, such as social and historical practices, involving different sectors of society. Thus, the vulnerability should take into account the relative size of the individual and the social site it occupies. In proposing other approaches, such as programmatic and social analysis, allows the payment of health status and different possibilities of intervention, always contemplating the participation of individuals. To intervene in situations of vulnerability is imperative to the development of actions that involve "social response" to the active participation of the population in the united search strategies enforceable and routing/addressing problems and health needs (19, 20).

The vulnerability is situated especially when it comes to public health. Junges (20) differentiates the public health clinic, the first is mainly concerned with the practice of diagnosis and treatment of individuals, while the second is focused on public policy in favor of the health of populations. Bridges and Espindola (21) argue that the benefits brought by scientific technology in healthcare are indisputable, since technological progress is crucial to the troubleshooting and the maintenance of life of people put the doctor-patient relationship, and delivered immersed the "temptation technology", brings the increase as a consequence, increasingly, the power conferred to make medical and its idealization as keeper of knowledge, leading, in turn, a reduction of listening and dialogue between the medicalization of life and death and a significant inaccuracy between the limits of life and death.

Doctors are faced with dilemmas in clinical practice: moral, ethical, legal, social, religious and economic. On these occasions, question their own values. By listening carefully to the stories of patients, health professionals broaden their perspectives, organize and integrate complex situations, which assists in conducting these difficult situations (17). For Castellanos (22), the doctor patient relationship has been the object of interest and reflection of the social sciences since the early decades of the twentieth century.

Today there is strong support of the importance of academic study of narratives as a central activity in practice and teaching of medicine. Conceptually, medicine and storytelling go together since multiple narrative possibilities are generated by the disease: the disease by itself, inscribed on the bodies, the autobiographical description of the patients, the transformation of these reports by physicians and the very course of the disease, exposing the relationship between language, sum, individual and time (17, 23).

According to Castellanos (22), by adopting the narrative perspective (especially the biographical) to

analyze the experience of chronic illness, I assumed that this experience must be understood in the trajectories (temporalities) experienced by the subjects. The diachronic perspective of life course and stages of illness intersects with the synchronic perspective of everyday families, impressing their meanings. By understanding these meanings we can grasp more properly the meanings of illness and of care, the constitution of the caregiver's role and strategies of coping with suffering, and the demands of the horizons opened by chronic illness. The narrative approach to ethical issues reveals the individual events of the experience of illness in all its contradictions and meanings for interpretation and understanding (17). Within this perspective, other factors, however, happen to produce a further deterioration in the relationship between doctor and patient (11). The development of science and technology for understanding environmental problems, which are both health problems, should consider how Freitas and Minayo (2, 4), to serve the social sense, political and universal right, which includes equity. The moral dilemmas are put in the frame of biography and culture of the patient.

Ethics is a social instrument that aims to contribute to the maintenance of social harmony. It aims to harmonize individual interests and collective interests. Social instrument designed to guide what should be done to achieve a fair and happy social life (25, 26). Strong and Schramm (25, 27) speak of values, principles and standards that serve as the basis for human behavior is the reflection, argue and provide rational justifications for the choices and moral decision making in concrete cases and situations. This results in reflections on the establishment of limits, criteria and parameters to prioritize what will be offered and to whom the services and health care will be offered (25), it is necessary to establish an interpersonal relationship of mutual trust and the caregiver watch the limits of its action, as may be injuring another principle, the autonomy of the client (9). Kovács (21, 28), under the reference principlism, which marks the development of bioethics is based on a tripod, called the "trinity bioethics".

The principles of autonomy, beneficence and justice, as bioethical reflections are comprehensive and

should always address all angles of the issues in focus, whether they are emerging characteristics, thus more exciting, they are more traditional, hence more conservatives. When it comes to everyday life, the emerging and exciting aspects give way to more traditional aspects and conservatives, but no less important or cease to constitute dilemmas to be analyzed (11).

According to Bettinelli, Waskiewicz, Erdmann and Pessini (21), health actions, in actuality, are marked-epistemological teaching, but above all, ethics: the "paradigm of healing" and "paradigm of care", for recognizing another in their own competence and their own knowledge as an act of partnership, while recognizing supposed to recognize each other in their uniqueness, but also in a more inductive, determine the project and set the contract — implied or actual — connecting the parts. Outlines are thus in ever sharper, the axis of bioethical issues in health. The doctor-patient relationship, deep and delivered the "temptation technology". This process is intended to accept the other in his difference as an actor and not as a standalone case to normalize. This involves taking the risk ratio. Muñoz (28) concludes that bioethics should be seen not as an overthrow of the classical medical ethics (so much that she adopted the basic principles, beneficence and non-maleficence), but their adaptation to new times, with the consequent change posture of the physician to better respond to ethical challenges raised by the social changes and the evolution of knowledge and technology.

CONCLUSION

Reflect the concept of vulnerability raises (re) think health practices, particularly in bringing to light the social experience of illness and hospitalization of the patient. In this sense, the meanings of illness, caring of pain, coping strategies, and the demands of the horizons opened by chronic illness, bringing the narrative as a tool appropriate to the plural dialogue in doctor-patient relationship. Under this view, the ethical territory requires the bioethical reflect, argue and provide constructions of knowledge towards the choices and making decisions in concrete cases and situations.

Sažetak

RANJIVOST I BIOETIKA KROZ ISKUSTVA O BOLESTI

Modesto Leite Rolim-Neto,^{1,2} Alberto Olavo Advincula Reis,² Sionara Melo Figueiredo de Carvalho,¹ Marcial Moreno Moreira,¹ Henrique Cesar Nascimento Ramalho-Filho,³ Ndia Nara Rolim Lima,³ Uilna Natércia Soares Feitosa,³ Maria de Ftima Bezerra de Alencar,³ Fernando Adami⁴

1 — Faculty of Medicine of Ceará Federal University — UFC, in Barbalha, CE, Brazil; 2 — Faculty of Public Health of University of São Paulo — USP, São Paulo, SP, Brazil; 3 — Suicidology Research Group — Barbalha, Brazil; 4 — Faculty of Medicine of ABC — São Paulo, Brazil

Uvod: Ranjivi ljudi su relativno ili apsolutno nesposobni da brane i čuvaju svoje interese. Ranjivost je antropološka osobina ljudi. Brazilsko društvo je odavno postalo bitan predmet proučavanja sociologa. U okviru toga, ranjivost u smislu odnosa doktor-pacijent je danas tema o kojoj se vrlo često diskutuje. **Cilj:** Ova studija teži da analizira već postojeće studije koje se tiču uvođenja ranjivosti kao zdravstvene teme, uporedo baveći se uključenim etičkim problemima, kao i doprinosima određenih autora ovom procesu. **Metod:** Ovaj članak se zasniva na podacima dobijenim iz baze Scientific Electronic Library Online (SciELO) i na podaci-

ma iz knjiga o ranjivosti, etici, odnosu lekar-pacijent. **Rezultati i diskusija:** Doktori se sučeljavaju sa dilemama u kliničkoj praksi: moralnim, etičkim, legalnim, socijalnim, religijskim, ekonomskim. U ovim situacijama, ispituju lične vrednosti. Samo pažljivim slušanjem pacijenata, zdravstveni radnici šire svoje vidike, bolje sagledavaju kompleksnost situacija, što im pomaže u savlađivanju teških situacija. **Zaključak:** Razmišljanje o samom konceptu ranjivosti i ugroženosti unapređuje svest zdravstvenih radnika, posebno u smislu boljeg razumevanja bolesti i hospitalizacije pacijenata.

Cljučne reči: ranjivost, bolest, depresija

REFERENCES

- Macklin R. Bioética, vulnerabilidade e proteção. In: Garrafa V, Pessini L, organizadores. Bioética: poder e injustiça. São Paulo: Loyola; 2003.
- Agamben G. Cequi reste d' Auschwitz. Paris: Rivages, 1998.
- Kottow MH. Bioética de proteção: considerações sobre o contexto latino-americano. In: Scramm FR, Rego BM, Palácios M. Bioética: riscos e proteção. Rio de Janeiro: UFRJ/Fiocruz, 2005.
- Paul P. A dimensão ética na educação para a saúde. Saude Soc. 2005; 14(1): 30–40.
- Nichiata LY, Bertolozzi MR, Takahashi RF, Fracoli LA. The use of the “vulnerability” concept in the nursing area. Rev Latinoam Enfermagem. 2008; 16(5): 923–928.
- Muñoz-Sánchez AI, Bertolozzi MR. Pode o conceito de vulnerabilidade apoiar a construção do conhecimento em Saúde Coletiva?. Ciênc Saúde Coletiva. 2007; 12(2): 319–324.
- Morais IM. Vulnerabilidade do doente versus autonomia individual. Rev Bras Saude Materno Infantil. 2010; 10(2): 331–336.
- Zoboli ELCP, Fortes PAC. Bioética e atenção básica: um perfil dos problemas éticos vividos por enfermeiros e médicos do Programa Saúde da Família, São Paulo, Brasil. Cad. Saúde Pública. 2004; 20(6): 1690–1699.
- Meira AR. Bioética e vulnerabilidade: o médico e o paciente. Rev Assoc Med Bras. 2004; 50(3): 249–250.
- Aran M, Peixoto-Junior CA. Vulnerabilidade e vida nua: bioética e biopolítica na atualidade. Rev Saúde Pública. 2007; 41(5): 849–857.
- Martines WRV, Chaves EC. Vulnerabilidade e sofrimento no trabalho do Agente Comunitário de Saúde no Programa de Saúde da Família. Rev Esc Enferm USP. 2007; 41(3): 426–433.
- Bertolozzi MR, Nichiata LYI, Takahashi RF, Ciosak SI, Hino P, Val LF, Guanillo MCLTU. Os conceitos de vulnerabilidade e adesão na Saúde Coletiva. Rev Esc Enferm USP. 2009; 43: 1326–1330.
- Coa TF, Pettengill MAM. A experiência de vulnerabilidade da família da criança hospitalizada em Unidade de Cuidados Intensivos Pediátricos. Rev Esc Enferm USP. 2011; 45(4): 825–832.
- Grossman E, Cardoso MHCA. As narrativas em medicina: contribuições para a clínica e ao ensino médico. Rev Bras Educ Med. 2006; 30(1): 6–14.
- Poirier S. Voice in the medical narrative. In: Charon R, Montello M (ed). The role of narrative in medical ethics. New York: Routledge; 2002.
- Ayres JRCM, França Junior I, Calazans G, Salletti H. Vulnerabilidade e prevenção em tempos de AIDS. In: Barbosa R, Parker R (org). Sexualidade pelo avesso: direitos, identidades e poder. Rio de Janeiro: RelumeDumar, 1999.
- Junges JR. Right to health, biopower and bioethics. Interface Comunic Saúde Educ. 2009; 13(29): 285–295.
- Pontes AC, Espindola JA, Duvalle ERM, Santos M. Bioethics. Centro Universitário S o Camilo. 2007; 1(1): 68–75.
- Castellanos M. Adoecimento crônico infantil: um estudo das narrativas familiares. S o Paulo: Hucitec, 2010.
- Kottow M. Literary narrative in medical practice. J Med Ethics: Med Humanities. 2002; 28: 41–4.
- Freitas CM. Problemas ambientais, saúde coletiva e ciências sociais. Ciênc Saúde Coletiva. 2003; 8(1): 137–150.
- Fortes PAC. Reflexão bioética sobre a priorização e o racionamento de cuidados de saúde: entre a utilidade social e a equidade. Cad Saúde Pública. 2008; 24(3): 696–701.
- Cortina E, Martinez E. Ética. S o Paulo: Edições Loyola; 2005.

24. Schramm FR. Da bioética privada à bioética pública. In: Fleury S (org.). Saúde e democracia: a luta do CEBES. São Paulo: Lemos Editorial; 1997.
25. Kovács MJ. Bioética nas questões da vida e da morte. *Psicologia USP*. 2003; 14(2): 115–167.
26. Guilhem D, Zicker F. Ética na Pesquisa em Saúde. Brasília: Editora UnB, 2007.
27. Bettinelli, LA, Waskiewicz J, Erdmann AL. Humanização do cuidado no ambiente hospitalar. In: Pessini L, Bertachini L. Humanização e cuidados paliativos. São Paulo: Loyola, 2004.
28. Muñoz DR. Bioética: a mudança da postura ética. *Rev Bras Otorrinolaringol*. 2004; 70(5): 578–579.

Correspondence to/Autor za korespodenciju

Modesto Leite Rolim-Neto
Ceará Federal University — UFC
Faculty of Medicine
R. Divino Salvador, 80
Barbalha, Ceará, Brazil
modestorolim@yahoo.com.br