

PRIVACY AND CONFIDENTIALITY IN HEALTH IN EPIDEMIOLOGICAL SURVEILLANCE: EXPERIENCE REPORT ON BIOETHICAL LOOK

Déborah Silva Sande*
 Tatiana Almeida Couto**
 Edite Lago da Silva Sena***
 Rita Narriman Silva de Oliveira Boery****
 Sérgio Donha Yarid*****

ABSTRACT

During work experience in epidemiological surveillance, Bahia, between the activities, there is mandatory reporting of injuries and illnesses. The study of the discipline of Health Science and in Bioethics, the Graduate Program in Nursing and Health, Master level, mobilized us to the resumption of daily experiences in health services involving bioethical issues that deserve critical reflection. The present study aimed to develop the reflection, according to bioethical perspective on the lived experience involving privacy and confidentiality in health, in the context of epidemiological surveillance. This is a descriptive study of the experience of mandatory reporting on activity in the epidemiological surveillance service of the Municipal Health Secretariat of the state of Bahia, in the period November 2011 to March 2013. Allowed us to perform that negligence in the application of bioethical principles under compulsory notification may interfere with the health of the user, it does not guarantee the integrity of their rights and reflects the inadequacy of ambience for consultations and the unpreparedness of professionals, with regard to the theoretical and practical knowledge of bioethics.

Keywords: Epidemiological surveillance. Bioethics. Confidentiality.

INTRODUCTION

This study is an experience report, according to bioethical perspective, about the privacy and confidentiality in health, seeking subsidies with a view to help in thinking about this issue, which constitutes itself as very relevant to the development of professional practice.

The concept of privacy refers to the protection of information or condition of inaccessibility to information, also covering the objects and the relationships between people⁽¹⁾. Confidentiality, in turn, it is a tacit agreement between the user and the provider that the information provided during the interview or consultation may not, by its end, be transmitted to others without explicit consent⁽²⁾.

The Brazilian Federal Constitution, in Chapter I, Article 5, Rights and Individual and Collective Duties in item XIV, states: "everyone is assured access to information and protection of the confidential source when necessary for professional exercise"⁽³⁾.

In epidemic surveillance, health professionals undertake actions aimed at health education on diseases and aggravations of compulsory notification, and the care of the affected user, which requires adherence to the ethical principles of privacy and confidentiality. These actions require adequate professional training, considering bioethical concepts and conceptions.

In the nursing graduation course, although since its inception already occurring insertions of students in practice settings, experience in epidemiological surveillance tends to happen later in the last semesters. This practice requires knowledge of theoretical approaches and bioethical principles, for example, the attendance of a service user in the context of mandatory reporting, when one intends to develop care from the perspective of wholeness, in which, among other things, one should avoid embarrassing situations when addressing the user in health services without adequate infrastructure.

It is assumed that the introduction of knowledge on Bioethics since the first half of the

*Nurse. Undergraduate student in Nursing and Health by University State of Southwest Bahia (UESB). Faria de Santana – Ba, Brazil. Email: enf_deborahsande@outlook.com

**Nurse. Undergraduate student in Nursing and Health by UESB. Faria de Santana – Ba, Brazil. Email: taty_couto@hotmail.com

***Nurse. Professor PhD of Health Department of UESB. Faria de Santana – Ba, Brazil. Email: editelago@gmail.com

****Nurse. Professor Post-Doctorate of Health Department of UESB. Faria de Santana – Ba, Brazil. Email: rboery@gmail.com

*****Dentist. Professor PhD of Health Department of UESB. Faria de Santana – Ba, Brazil. Email: syarid@hotmail.com

undergraduate nursing may allow better use by the student, the discussion should continue horizontalizing the syllabus of all the subjects of the course. So the bioethics discipline being administered in a procedural way, and even before the inclusion of students in the health field stage, as to during this period, tends to assure them to be better prepared for the making of decisions on ethical dilemmas by experienced professional in their daily performance in health⁽⁴⁾.

In this sense, it is considered that the inclusion of bioethics in the integrated curriculum of Nursing offers fundamental contributions to education in the area, since it enables moments of discussion and ethical reflection for decision making in various practical situations regarding nursing assistance⁽⁵⁾. Thus, it is necessary to promote discussions beyond conventional dilemmas such as organ donation and transplantation, euthanasia, stem cell treatment, in vitro fertilization, among others, and engage discussions on bioethics of everyday life, which includes the various conflicts that engender human relations.

The relationships between health professionals and users are permeated by ethical and disciplinary elements, being covered with very specific nuances, determined by the nature of the profession and its exercise, increasingly complex due to the new aspects of scientific development and social relationships⁽⁶⁾. Thus, the conduct of some professions may be subject to codes of behavior peculiar to the activity, and especially the social relationships established by it.

With a lineup that includes the approach of Bioethics procedurally, health professionals will feel better prepared to act in services involving activities of compulsory notification in the context of epidemiological surveillance, which will favor the exercise of privacy and confidentiality the information shared by the users.

The preparation of the professional to act in this service is very important, since the epidemiological surveillance is characterized as an essential tool for the enforcement of actions to control diseases and aggravations; is a relevant public health tool for planning,

organization and operation of health services, and standardizing the technical activities. Therefore, it is a service that involves mutually specific and complementary functions, continuously developed in order to know the behavior of the selected disease or aggravation, and from that, promoting relevant intervention measures⁽⁷⁾.

In assistance, healthcare professionals have access to and receive private information from users about their complaints, disease history and health needs, which requires the preservation of privacy and confidentiality⁽⁸⁾, in order to contribute to the maintenance of work quality.

From the observation of various health services has been highlighted the shortage of professionals in relation to subjective vision that is expected of all health practices. This could lead to disrespect of user rights, so it takes a commitment to the ambience, improvement in working conditions and the care offered, so that there is awareness of health needs, desires and the interests of the different subjects⁽⁹⁾.

The study of the discipline of Bioethics in Science Graduate Program Health in Nursing and Health, Master level, led to the resumption, with critical assessment, daily experiences of involving bioethical issues in health services. Thus, the present study aimed to develop a reflection, according to bioethical perspective on the lived experience involving privacy and confidentiality in health, in the context of epidemiological surveillance.

METHODOLOGY

This study is descriptive in nature and relates the experience of mandatory reporting activity in epidemiological surveillance of the Municipal Health Service (SMS) of the State of Bahia, in the period November 2011 to March 2013. The systematization of the narrative involved the following steps: a) survey of articles, books and documents that addressed the following themes: surveillance, bioethics, privacy, confidentiality and mandatory reporting; b) critical reading of the material; c) description of the experience of compulsory notification service within the context of epidemiological surveillance; d) articulation of this experience with a reflection about the privacy and confidentiality in health.

RESULTS AND DISCUSSION

As explained in the introduction, the study was to develop a reflection, according to bioethical perspective on the experience involving privacy and confidentiality in health, in the context of epidemiological surveillance.

In the SMS where the experience was reported, exists a sector in which mandatory reporting and the research on diseases and aggravations are performed, apart from the conducting of examinations. In this service, there is a team consisting of nurses, doctors and physiotherapists who are responsible for implementation of the compulsory notifications.

When the user arrives at the service desk, the receptionist requests the presence of a professional to perform the notification and investigation of the case, although this professional doesn't always seems to be motivated to perform the procedures. Also, by not having a specific room, reporting procedures and research, is sometimes done in the waiting room, which possibly causes embarrassment to the user, because they occur in the presence of others, which may begin to question him/her about his/her personal life and his/her disease, which interferes with the consultation. One realizes with that, that there are flaws in the preservation of that user privacy and confidentiality of information provided by him/her.

At the end of the investigation, the professional usually orders tests for which, for their realization, the service has a specific room, and the time of collection of the material, the professional tends not to close the door, because it is an inappropriate environment. However, during the procedure, the investigation files are left in places of easy access, allowing its visualization by the clientele.

Professional conduct of this nature has been shown in the routine of the SUS services in many regions of the country. Although the system has been established based on a broad social movement that advocated the right to health for all, regardless of social class, which involved the participation of students, teachers, researchers, health workers and also the representative sectors of the populations poorest, the SUS has been seen by most of the population and, specifically, the most needy, as a system of

care for the poor. Because the system is still not accessible to all people, those that can be attended, even precariously, are grateful and many of them do not question this, thinking it is to be that way.

The SUS, as any other health system, requires adequate infrastructure, which includes facilities, equipment, labor, science and technology, which entail the offering of the services to the population.

Thus, the epidemiological surveillance system, like all others, must be structured so that they maintain the necessary and sufficient conditions for the development of actions by those professionals involved. Among the structural demands of this service, a proper official documents file location is crucial, as well as the organization of users' documents classified as cases of monitoring, and also of all cases notified by the service.

As highlighted in the experience report, sensitive information about users and may be shared with other users of the service, not so much ensuring the privacy of any user to the confidentiality of information provided by him/her. Therefore, there is difficulty with the reception of users and interference on the quality of the attendance. This fact, in addition to violating ethical rules, may embarrass those involved and impair the bond established between professional and service user⁽¹⁰⁾.

Preserving user's right to privacy and confidentiality is supported, among other legal instruments, by the Universal Declaration of Human Rights⁽¹¹⁾, in its Article 12, which states: *"No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation."* An aspect that may occur in the event the user experiences a situation of embarrassment for health intervention, which involves research on a certain pathology and mandatory reporting.

When a health care provider performs a service to the user, it is necessary to stay attentive to ensure their well-being and protection of their dignity as human beings; ie, it is imperative to consider the bioethical principles in order to mediate the relationship between science and ethics in its professional interaction with the patient⁽¹²⁾.

In the daily operations of the nursing professional in the context of nurse-user relationship, there are frequent situations involving ethical dilemmas, both for their involvement in contentious circumstances as by constant relations with users, families and others in the area of the work process⁽¹⁰⁾.

Ensuring the patients' privacy is contained in the Code of Ethics for Nursing Professionals in the chapter on responsibility and duties, Art. 19, which compromises the nurse "respect pudency, privacy and intimacy of human beings, throughout their entire life cycle, including in situations of death and post-death"⁽¹³⁾. In this sense, the nurse in view of his daily professional activity, needs to know and respect the patients' information to ensure privacy and confidentiality in decision making.

It's important to emphasize that the user, when appearing in some kind of health service, whether public or private, during the consultation, and reporting his/her life story to the professional, he/she must be able to rely on the confidentiality of any personal information provided as well as the right to preservation of his/her privacy⁽¹⁴⁾.

In this regard, the Code of Ethics for Nursing Professionals⁽¹³⁾, in Chapter II, Art. 81, highlights the importance of ensuring the confidentiality and duty by reason of professional activities, and the following: "Refrain from disclosing confidential information he/she is aware of by virtue of their professional practice, to persons or entities that are not bound to secrecy ". In sequence, art. 82, about the responsibilities and duties, reads: "maintain secrecy about the confidential fact that he/she became aware of as a result of their professional activities, except in cases provided by law, court order, or with the written consent of the person concerned or his legal representative". So it is up to the nurse's competence in making decisions, however, without distancing himself from the user and without claiming to be the holder of knowledge, or, considering the user as a liability⁽¹⁵⁾.

Returning to the focus of this study's experience – the attendance on compulsory notification and commitment to privacy and confidentiality of users – it is recognized that this is a question inscribed in the context of

bioethics of protection, since those served are vulnerable, and many of them members of minorities who suffer restrictions of freedom due to social inequality and lack of empowerment to address the inadequate care and fight for the guarantee of rights to the execution by the State of public policies for quality⁽¹⁶⁾, with prepared health professionals, not only technically, but with the foundation of traditional values in distinct, to deal with conflicts and moral dilemmas, characteristic of a country considered peripheral, as is the case of Brazil.

In this reflection on experience it is possible to show that the theoretical contents on bioethics, probably developed in undergraduate courses in health, have not been adequately applied in the profession, in a way to ensure user confidence in professional and service offered, especially when it comes to vulnerable populations. The importance of the discussion of the principles of bioethics in nursing education is necessary, because these guidelines in bioethics seek to train professionals able to devote themselves to the practice of nursing with effective and responsible performance⁽⁴⁾.

The reflection of this experience shows the bioethics as an approach to risk and protection in the interests of all employees working in the area of health, both teachers in the context of education and ethics training, as to service professionals, as well as for the researchers dealing with conflicts of interest arising from their relationships with research funders, putting individuals and population groups in situations of vulnerability and susceptibility at risk.

In light of the principles of bioethics and epidemiological surveillance, one realizes that health care without the guarantee of the integrity of users' rights services is a problem that may be affecting the various regions of Brazil and not only Bahia. Besides the inadequacy of ambience for consultations, with regards the physical and functional structure and infrastructure of public health services, the professionals are unprepared in relation to theoretical and practical knowledge of bioethics.

CONCLUSION

The narration of the experience allowed us to reflect on the reality of a compulsory notification

service within the context of epidemiological surveillance, according to bioethical perspective. The construction of this reflective material allowed to rethink health care under the more global perspective, in the sense of valuing human life in its complexity, with emphasis on the subjective dimension; recognizing that all behavior is communication, which signals the attachments produced in the professional-user relationship and vice versa.

One can also see the importance of bioethics horizontalizing our practices in day to day health services and in other contexts of the territory where one can produce care. There was mobilization on resuming teaching, research and

extension experiences that, when experienced in the context of training, can influence the role of professionals in the public health system and the lives of users.

That way, it is believed that reading this material will contribute to stimulate debates in academia, among working professionals, and within the public health management, about the need for change in the physical and functional structure of epidemiological surveillance services, in order to provide a dignified and respectful assistance to users while preserving the bioethical principles and human rights.

PRIVACIDADE E CONFIDENCIALIDADE EM SAÚDE NA VIGILÂNCIA EPIDEMIOLÓGICA: RELATO DE EXPERIÊNCIA SOB O OLHAR BIOÉTICO

RESUMO

Durante experiência de trabalho em vigilância epidemiológica, na Bahia, entre as atividades desenvolvidas, destaca-se a notificação compulsória de agravos e doenças. O estudo da disciplina Bioética em Ciência da Saúde, do Programa de Pós Graduação em Enfermagem e Saúde, nível de Mestrado, mobilizou-nos à retomada de vivências cotidianas nos serviços de saúde que envolve questões bioéticas e que merece reflexão crítica. O presente estudo teve como objetivo desenvolver uma reflexão, segundo a perspectiva bioética, sobre a experiência vivenciada, envolvendo privacidade e confidencialidade em saúde, no contexto da vigilância epidemiológica. Trata-se de estudo descritivo da vivência em atividade de notificação compulsória no serviço de vigilância epidemiológica da Secretaria Municipal de Saúde de município da Bahia, no período de novembro de 2011 a março de 2013. Permitiu-nos perceber que a negligência na aplicação de princípios bioéticos no âmbito da notificação compulsória pode interferir na saúde do usuário, pois não garante a integridade de seus direitos e reflete a inadequação da ambiência para os atendimentos e o despreparo dos profissionais, no que se refere ao conhecimento teórico-prático de bioética.

Palavras-chave: Vigilância epidemiológica. Bioética. Comunicação sigilosa.

PRIVACIDAD Y CONFIDENCIALIDAD EN MATERIA DE SALUD EN LA VIGILANCIA EPIDEMIOLÓGICA: RELATO DE EXPERIENCIA EN LA MIRADA DE LA BIOÉTICA

RESUMEN

Durante la experiencia de trabajo en materia de vigilancia epidemiológica, Bahia, entre las actividades, es obligatoria la notificación de lesiones y enfermedades. El estudio de la disciplina de Ciencias de la Salud de Bioética de Máster, nos movilizó a la reanudación de las experiencias cotidianas de los servicios de salud relacionados con las cuestiones de bioética que merecen la reflexión crítica. El presente estudio tuvo como objetivo desarrollar una reflexión, de acuerdo con la perspectiva de la bioética en la experiencia vivida que implica la intimidad y la confidencialidad en la salud, en el contexto de la vigilancia epidemiológica. Se trata de un estudio descriptivo de la experiencia de la notificación obligatoria de la actividad en el servicio de vigilancia epidemiológica de la Secretaría Municipal de Salud del Estado de Bahia, en el período noviembre 2011 la marzo 2013. Nos permitió darnos cuenta de que la negligencia en la aplicación de los principios bioética bajo notificación obligatoria puede interferir con la salud del usuario, que no garantiza la integridad de sus derechos y refleja la insuficiencia de ambiente de consultas y la falta de preparación de los profesionales, en relación con el conocimiento teórico y práctico de la bioética.

Palabras clave: Vigilancia Epidemiológica. Bioética. Confidencialidad.

REFERENCES

1. Beauchamp TL, Childress JF. O relacionamento entre o profissional e o paciente. In: Beauchamp TL, Childress JF. Princípios de ética Biomédica. São Paulo: Edições Loyola; 2002. p. 425- 494.
2. Santos MFO, Santos TEO, Santos ALO. A confidencialidade médica na relação com o paciente adolescente: uma visão teórica. Rev bioét. [on-line]. 2012

- ago-jun. [citado 2014 jul 01]; 20(2): 318-325. Disponível em: revistabioetica.cfm.org.br/index.php/revista_bioetica/article/view/625.
3. Brasil. Constituição da República Federativa do Brasil. Diário Oficial da União [on-line]. 05 out 1988. Senado Federal. Brasília (DF); 2013. Disponível em: https://www.planalto.gov.br/ccivil_03/Constituicao/ConstituicaoC3%A7ao.htm.

4. Couto Filho JCF, Souza, FS, Silva SS, Yarid S, Sena ELS. Ensino da bioética nos cursos de Enfermagem das universidades federais brasileiras. *Rev bioét.* [on-line]. 2013 ago-jan. [citado 2013 abr 28]; 21(1):179-85. Disponível em: http://revistabioetica.cfm.org.br/index.php/revista_bioetica/article/view/735/870.
5. Pessalacia JDR, Oliveira VC, Rennó HMS, Guimarães EAA. Perspectivas do ensino de bioética na graduação em enfermagem. *Rev bras enferm.* 2011 mar-abr. [citado 2014 maio 6]; 64(2):393-398. Disponível em: http://www.scielo.br/scielo.php?pid=S0034-71672011000200029&script=sci_arttext.
6. Lopes JCN. Segredo médico e o direito humano à privacidade: uma abordagem jurídica. *Rev bioét.* [on-line]. 2012. [citado 2014 jul 15]; 20(3):404-412. Disponível em: http://revistabioetica.cfm.org.br/index.php/revista_bioetica/article/view/759/812.
7. Ministério da Saúde(BR). Secretaria de Vigilância em Saúde. Departamento de Vigilância Epidemiológica. Guia de vigilância epidemiológica. Série A. Normas e Manuais Técnicos. 7a ed. Brasília(DF): Ministério da Saúde; 2009.
8. Seoane AF, Fortes PAC. A percepção do usuário do Programa Saúde da Família sobre a privacidade e a confidencialidade de suas informações. *Saúde Soc.* [on-line]. 2009 nov-jun. [citado 2013 abr 06]; 18(1):42-49. Disponível em: <http://www.scielo.br/pdf/sausoc/v18n1/05.pdf>.
9. Ministério da Saúde(BR). Política Nacional de Humanização. Humaniza SUS. Brasília(DF): Ministério da Saúde; 2004.
10. Przenyczka RA, Kalinowski LC, Lacerda MR, Wall ML. Conflitos éticos da enfermagem na atenção primária à saúde e estratégias de enfrentamento. *Cienc cuid saude.* [on-line]. 2011 abr-jun. [citado 2013 maio 17]; 10(2):330-337. Disponível em: <http://periodicos.uem.br/ojs/index.php/CiencCuidSaude/article/view/12849>.
11. Brasil. Ministério da Justiça. Declaração Universal dos Direitos Humanos. [on-line]. 1948. [citado 2013 abr 08]. Disponível em: <http://www.brasil.gov.br/sobre/cidadania/direitos-do-cidadao/declaracao-universal-dos-direitos-humanos>.
12. Ramos DLP, Junqueira CR. Bioética-conceitos, contexto, fundamentos e princípios. In: Ramos DLP. *Fundamentos de Odontologia-Bioética e Ética Profissional.* Rio de Janeiro (RJ): Guanabara Koogan; 2007. p. 22-34.
13. Brasil. Conselho Federal de Enfermagem. Código de Ética dos Profissionais de enfermagem. Rio de Janeiro: Conselho Federal de Enfermagem; 2007.
14. Brasil. Ministério da Saúde. Carta dos Direitos dos Usuários da Saúde. 2a ed. Brasília (DF): Ministério da Saúde; 2007.
15. Sapiro CM. As teorias de desenvolvimento sociomoral e a formação dos profissionais de saúde. In: Schramm FR, Rego S, Braz M, Palácios M. *Bioética: riscos e proteção.* 2a ed. Rio de Janeiro: Editora UFRJ: Editora Fiocruz; 2009. p. 177-192.
16. Schramm FR. É pertinente e justificado falar em bioética de proteção? In: Porto D, Garrafa V, Martins GZ, Barbosa SN. *Bioéticas, poderes e justiça: 10 anos depois.* Brasília(DF): Conselho Federal de Medicina/ Cátedra Unesco de Bioética/Sociedade Brasileira de Bioética; 2012. p. 127- 141.

Corresponding author: Déborah Silva Sande. Rua Intendente Abdôn, nº 564, Queimadinha, Feira de Santana, Bahia, Brasil. CEP: 44050-024. E-mail: enf_deborahsande@outlook.com.

Submitted: 01/06/13

Accepted: 08/09/14