Privacy and confidentiality: Ethics in telemedicine

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Introduction: In countries such as Guatemala and others in which telemedicine and/or telehealth programs are in the implementation stages, with limitations in terms of leadership of the governing bodies within the State, it is necessary to be aware of some important aspects, such as privacy, confidentiality, related to ethics. That is why the article describes some of the particularities of privacy, confidentiality, and anonymity in the field of ethics and telemedicine. Objective: to demonstrate the ethical principles that should prevail in the development of telemedicine. Specific Objectives: 1. to describe the relation between respect for privacy and protection; 2. to explain the relation between confidentiality, telemedicine, and telehealth. Method: the method used is documentary, descriptive, and an exhaustive search of articles related to the subject was carried out, organizing them in two sections. The first will define and distinguish the concepts of privacy and confidentiality and show their singular characteristics in relation to ethics. The second will analyze some current debates and criticisms about anonymity. Results: The main result identified to be considered is that quality standards guarantee the security of information, and it must be managed correctly, using a systematic process, documented, and known by the whole organization, from a risk approach.

Keywords: Privacy; Confidentiality; Ethics in Telehealth

Privacidad y confidencialidad: Ética en telemedicina

Introducción: En países como Guatemala y otros en que los programas de telemedicina y/o telesalud están en fases de implementación, con limitaciones en cuanto al liderazgo de los entes rectores dentro del Estado, se hace necesario el conocimiento de aspectos importantes como la privacidad, confidencialidad, relacionadas a la ética. Es por ello por lo que el artículo describe algunas de las particularidades, de la privacidad, la confidencialidad y el anonimato en el ámbito de la ética y la telemedicina. Objetivo: Evidenciar los principios éticos que deben prevalecer en el desarrollo de la telemedicina. Objetivos Específicos: 1. Describir la relación entre respeto de la privacidad y protección, 2. Explicar la relación entre confidencialidad, telemedicina y telesalud. Método: el método utilizado es documental, descriptivo se realizó una búsqueda exhaustiva de artículos relacionados al tema, organizándolo en dos apartados. El primero definirá y distinguirá los conceptos de privacidad y confidencialidad y mostrarán sus características singulares con relación a la ética. El segundo, analizará algunos debates y críticas actuales en torno al anonimato. Resultados: El principal resultado identificado a tomar en cuenta es que los estándares de calidad garantizan la seguridad de la información y debe ser gestionada correctamente, se debe hacer uso de un proceso sistemático, documentado y conocido por toda la organización, desde un enfoque de riesgo.

Privacidade e confidencialidade: Ética em telemedicina

Introdução: Em países como a Guatemala e outros onde os programas de telemedicina e/ou telessaúde estão em fase de implantação, com limitações quanto à liderança dos órgãos de governo dentro do Estado, é necessário conhecer aspectos importantes como privacidade, confidencialidade, relacionados à ética. É por isso que o artigo descreve algumas das particularidades da privacidade, confidencialidade e anonimato no campo da ética e da telemedicina. Objetivo: Evidenciar os princípios éticos que devem prevalecer no desenvolvimento da telemedicina. Objetivos Específicos: 1. Descrever a relação entre respeito à privacidade e proteção, 2. Explicar a relação entre confidencialidade, telemedicina e telessaúde. Método: o método utilizado é documental, descritivo, foi realizada uma busca exaustiva de artigos relacionados ao tema, organizando-o em duas seções. A primeira definirá e distinguirá os conceitos de privacidade e confidencialidade e mostrará suas características únicas em relação à ética. A segunda analisará alguns debates e críticas atuais em torno do anonimato. Resultados: O principal resultado identificado a ter em conta é que os padrões de qualidade garantem a segurança da informação e esta deve ser gerida corretamente, deve ser utilizado um processo sistemático, documentado e conhecido por toda a organização, a partir de uma abordagem de risco. Palavras chave: Privacidade; Confidencialidade; Ética em telessaúde



Introduction

Ethics can be defined as the science of moral conduct, since, by carrying out a thorough analysis of society, it establishes how all individuals who live in it should act or behave. This philosophical discipline is linked to the rules, which serve as a basis for underscoring a difference between good and evil. Professional ethics is the set of values and norms that allow for a better development in professional activities, all of which is linked to the code of ethics of health personnel, which refers to the moral obligations and social treatment that a person assumes when providing their services in a health center, on a daily basis.¹ The work team of Guatemala raises its interest in the article, derived from the different foundations and experiences presented throughout the telehealth course, and deems it necessary to specify aspects that are indispensable in the work that is carried out with users who demand health care. This is one of the determining aspects in health care - confidentiality, which is a property of information and that should be accessible only to authorized personnel, to ensure its protection through professional secrecy, and that can be disclosed only with the consent of the person or persons involved. And it becomes a fundamental element of professional ethics that must be integrated with the principles of respect, welfare, among others. The objective is to demonstrate the ethical principles that should prevail while developing telemedicine; To describe the relation between respect for privacy and protection; and also to explain the relation between confidentiality, telemedicine, and telehealth.

Method

The method used is documentary, descriptive, and an exhaustive search of articles related to the subject was carried out, organizing findings in two sections. The first will define and distinguish the concepts of privacy and confidentiality and show their unique characteristics in relation to ethics. The second will analyze some current debates and criticisms about anonymity.

While performing the review in advanced search engines

By placing the terms ethics and privacy in all languages we get the following information: 75,400 results. By breaking it down by years, from 2018 up to date, we get 15,100.

The article by Toboso, M. et al. (2019) indicates what is related to ethics, robotics and assistive technologies and presents:

"Emerging technologies such as robotics or Artificial Intelligence have an important potential for application in social practices related to the protection of human vulnerability, such as health care and promotion. Reflection on the incorporation of these new technical-scientific mediations must take into consideration the opportunities they offer as well as the risks they entail; additionally, to what extent they will, in a deep sense, transform such practices, and how their ethical and legal legitimacy will be preserved unscathed."²

Results

Respect for privacy and protection of confidentiality

To address this issue, it should be considered that the ethical issues included under the notions of "privacy" and "confidentiality" are acknowledged and addressed in the context of care through teleconsultations and/or telemedicine, due to the possibility of providing data to patients.

From the regulatory standpoint, efforts have been made to standardize the privacy of information at the international level (ISO 27001 standards - Information Security Management Systems), where information security has been defined as the preservation of confidentiality, integrity and availability, as well as that of the systems involved in its treatment, and these terms form the basis of information security: a) Confidentiality: the information is not made available or disclosed to unauthorized individuals, entities or processes; b) Integrity: maintaining the accuracy and completeness of information and its processing methods; c) Availability: access to and use of information and the information processing systems by authorized individuals, entities or processes when required.³

The necessary steps must be taken to ensure compliance and, in each country, to promote internal legislation and respective regulations to guarantee the privacy and confidentiality of each patient's information.

According to the Code of Ethics for Healthcare Professionals of the International Medical Informatics Association (IMIA), there are specific principles of informatics ethics, which are summarized as follows: privacy and availability of information, transparency, security, access, legitimate safeguarding, least invasive alternative, principle of responsibility. As we can see, all the specific principles of computer ethics are basically focused on protection of information privacy, but from a purely technical viewpoint. It implies that every healthcare professional, regardless of the mechanism used for healthcare, must proceed within the framework of the code of ethics, which, in our country, is a document that exists for professional ethical performance.

From a global perspective, ethics and morals are situated within a cultural context and, as such, express hegemonic values and customs within a given society. These values and customs come from a long civilizing process with roots in primitive peoples and, subsequently, influenced by the colonizers, as in the case of Latin America. The phenomenon of globalization experienced by the post-modern world has revealed cultural differences and created problems that are difficult to solve.

"That which I see and hear during or outside of treatment concerning the lives of men and which I do not deem it necessary to report, I will keep to myself and regard such things as a secret."⁴

The Hippocratic roots have not been corroded by the weather. On the contrary, they have been solidified as constitutional principles and as duties in the codes of ethics of health professionals.

The constitutions of some countries, such as the Brazilian, have legislated on the privacy of individuals -"The privacy of private life, honor and image of individuals are inviolable. The right to compensation for material or moral damage resulting from their violation is guaranteed". (Paragraph X of Article 5 of the Brazilian Constitution).⁴

Privacy refers to the ability of human beings to manage their world of values freely and privately. These may be religious, political, philosophical, cultural, hygienic, and sexual values, among others.

Privacy is, therefore, a right that protects the individual against the intrusion of others into their space without their consent.

It must be accountable in the control of the information, which must be intimate and secret and prevent the dissemination of this information, since it is private.

Confidentiality is also a right. It is the right of individuals not to have their personal data disclosed or used without their authorization by those who could have had access to such data.

Secrecy is a duty. It is the duty of persons who know data about others not to disclose it without consent or without legal permission. The right of confidentiality is subject to the obligation of secrecy.

Notwithstanding this, these generic concepts are extremely important for patients and healthcare professionals, regardless of whether healthcare practices are face-to-face or virtual. The compatibility of information and communications technology (ICT) with the abovementioned rights and duties should be discussed, taking as a general framework ethics and privacy of information as a right and obligation of providers in respect of the primacy of the Human Being. This reflects the values and moral ethical principles of the different professionals and professions.

Current debates on anonymity in telemedicine - telehealth

In Mexico (2001), the National Medical Arbitration Commission presented recommendations to improve the practice of medicine, all of which with a profound ethical sense, which are presented in the following list, and which are adapted for use in Telemedicine, as well as others that involve Remote Medical Care.⁵

1. Respectful doctor-patient relationship, where elements such as timeliness of care, adequate communication, confidentiality, and information about the prognosis involving Telemedicine intervention are indicated.

2. Informed consent prior for an intervention with risk, to be the subject of a research project or intervention by [Telemedicine].

3. Acting in accordance with current medical knowledge, avoiding defensive medicine.

4. To serve patients when authorized to do so, by means of the title or diploma of the specialty in question; not to participate in criminal practices such as abortion, euthanasia, and false medical certificates.

5. To refer patients when they do not have the resources for their care.

6. To deal with emergencies; not to abandon the patient, including in cases of strike, catastrophe, or epidemics, even when this poses a risk to the physician.⁵

7. To value medical care by [Telemedicine] to address emergencies. 6

8. An understanding, attentive, respectful, and protective attitude towards the patients should be observed, safeguarding their integrity, the medical information provided, privacy and confidentiality in the use of ICT, both for the patient and for the tele-consulting physician.

9. Complete and understandable information should be provided to the patient about the entire [tele-consultation] process.

10. Full satisfaction shall be sought for the patient and their family members for the care provided through [Telemedicine].⁷

11. The presence of persons outside the teleconsultation process shall not be allowed, thus safeguarding the patient's confidentiality and privacy.⁸ Another debate that has taken place refers to the following:

1) It is currently expected that the countries within the health system they possess conduct a deep reflection on the applicability and usability of e-health. Its generality requires a debate on the ethical and jurisdictional aspects involved in its applications from a global perspective.

The possibility of exchanging good practices in healthcare at the local, state, and international levels

has never been as great as it is today. Language barriers were once an impediment and have now been overcome by technology and established legislation.

2) The organizations involved in health at the international level must articulate with the bodies responsible for the exercise of health professions in each country, to build policies that allow for viability and that can make official any form of exchange in this field.

This is a challenge, since it is not a straightforward process: it involves technical and bureaucratic issues that need to be overcome. In addition, there are underlying legal and moral issues specific to each country and, as these are international relations, the complexity is even greater.

The issue of confidentiality in telemedicine should become a responsibility of each of the countries involved, taking ethics as a substantive frame of reference, and deriving actions that help to make viable, first the decision to officially implement this form of distance support, legislate it and conclude it with the ethical framework that guarantees confidentiality of information.

Conclusion

One of the great challenges that countries face when using telemedicine or telehealth is implementation of quality standards to ensure that information security is effectively managed, using a systematic, documented and known process throughout the organization, from a risk approach.

Besides that it is important to implement a working team for the organization of standards that guarantee confidentiality of information.

The ISO 27001 standards - Information Security Management Systems, should become the regulatory framework to ensure the security and confidentiality of user information.

Finally, the training of human resources with the integration of the ethics and a telemedicine component is required.

References

1. Adrián Y. Definición de Ética. Available from: https://conceptodefinicion.de/etica/.

2. Martín MT, Payá MA, Castro DL, Ausín T. Ethics, robotics and assistive technologies. Dilemata [Internet]. 2019 May 31;(30):i-iv. Available from: https://www.dilemata.net/revista/index.php/dilemata/art icle/view/412000285

3. Normas ISO 27001 – Sistemas de Gestión de la Seguridad de la Información 2013.

4. Messina LA. Desarrollo de la telesalud en América Latina: aspectos conceptuales y estado actual. CEPAL. Chile, 2013 Oct;614. Available from: http://repositorio.cepal.org/handle/11362/35453.

5. Comisión Nacional de Arbitraje Médico. Recomendaciones para mejorar la práctica de la medicina. [en línea]. México; 2001. [Consultado 11 jul 2016]. Available at:

http://www.conamed.gob.mx/comisiones_estatales/coe samed_tlaxcala/publicaciones/pdf/RECOMENDACION ES_MEJORAR_PRACTICA_MEDICA.pdf

6. Consentimiento informado antes de una intervención con riesgo, para ser sujeto de un proyecto de investigación o intervención por [Telemedicina].

7. Chile. Ministerio de Salud. Programa Nacional de Telesalud: en el contexto de Redes Integradas de Servicios de Salud. Subsecretaría de Redes Asistenciales. 2018;76. Available from: https://biblioteca.digital.gob.cl/bitstream/handle/12345 6789/3635/Programa%20Nacional%20de%20Telesalu d.pdf?sequence=1&isAllowed=y

8. Gas HGA. Ética Médica: Consentimiento informado. [Documento suelto en línea] [Accessed on July 12, 2016]. Available at: http://www.facmed.unam.mx/eventos/seam2k1/Ponenc ia_nov.pdf

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