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RESEARCH ARTICLE

BIG DATA OPPORTUNITY AND PRIVACY OF PATIENT DATA

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Abstract

The use of massive data in medicine through Big Data is favouring the diagnosis and treatment of diseases (Agarwal, Adhil, and Talukder 2015; He, Ge, He, 2017; Tan, Gao, Koch, 2015). In parallel, this process has begun to be regulated based on new rights of protection of citizens' data, considering the challenging problems of privacy and security of big data (Ristevski, & Chen, 2018). These circumstances modify the role of each of the components of the care relationship that is generated between the doctor and the patient and his family. This situation empowers the patient as a data holder or information protagonist. The analysis of the data can help to change the diagnosis or treatment of the disease and therefore its use is considered necessary in order to change the trajectory and treatment of the diseases. In this direction, a relationship of trust, privacy and security between patients and professionals and / or health centers must be built. This transmission of information must be private and protected from cyber-attacks as well as data theft, etc. Big Data allows to analyze a large volume of varied data, at high speed generating new values based on the data used (Morente, 2019), which is a great advance. This computer tool is capable of performing analysis processes in record time unlike the time spent with other methodologies. This activity must be carried out from the reflection based on a technological ethic that respects the privacy of the person. The hand of the man who intervenes in this process must decide between what is technically possible and what proceeds ethically according to the limits set by the different laws on privacy, security and confidentiality.

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Introduction:-

Information technologies have come to change the way we interact and ultimately our way of life, we are immersed in a phase of maturity of both hardware and software, which would lead us to the affirmation that we are at the doors of a new knowledge centered revolution. All this thanks to the immense availability of data and the growing technological capabilities to treat and convert them into useful information (Alonso and Redondo, 2019). The use of Big data analysis applications can improve health care for patients in order to prevent the spread of diseases among other possibilities (Agarwal, Adhil, and Talukder 2015; He, Ge, He, 2017; Tan, Gao, Koch, 2015), thus avoiding its human, social and economic impact. The development of the New Information and Communication Technologies (ICT), allows any problem for which there is stored historical data to be a problem that can be treated by data mining techniques (Alujan, 2001: 483).

The relationship between the patient and the medical professional is determined by a cultural context. Every culture has its specific ethical standards. Although they are different according to the time, the country and the particular characteristics of each town, agree to be at the service of the orderly course of life in common. Today, an important factor in the relationship between the patient and the professional is the registration of patient data in the Clinical History or Digital Health History, unlike previous health care processes, where no records were made.

It is important that patients are aware of what data is provided, how they are treated and how important they are. The data of the patients that are recorded in their Digital Medical Record are kept by professionals and institutions. Therefore, it is necessary that both professionals and centers become co-responsible for their protection. This protection must be based on a will that defends the rights of privacy and security of patient data. In that will, explicitly or implicitly hides a concrete image of man and the realization of human coexistence, in which human values of respect for dignity are considered. The mental representation of man becomes a point of support for the detailed description of the ethical aspects of human work: everything that is in the line of true humanity will be ethically good, while what is oriented to liquidate it

Currently, most patients are trained and informed about their disease, willing at the same time to share information about their ailments in order to find new treatments. These patients need to find the most appropriate way to make their own decisions regarding the management of their disease together with the medical team. The Internet allows a new way to receive and offer health services (Basagoiti, 2011). Users abandon a passive role in the consumption of information, and adopt an active role in the generation, improvement and exchange of new health content. The patient is aware that their collaboration can contribute to improving the quality of life of society. The health system can be transformed into an intelligent system, of a collective intelligence, which is no longer individual (personal or institutional) but of networks that can respond to the imperative need for clarity on what to do and how to face the future (De La Higuera, 2019). Thus, the figure of the patient or connected patient arises, which is nothing more than the expert patient who uses the Internet and its tools (Basagoiti, 2011: 52).

Most countries agree that medical data are very sensitive and legally belong to patients (Viceconti, Hunter, and Hose, 2015). Cyberspace introduces a new security paradigm, called by its nature to replace its predecessors because cybersecurity is not simply cyberspace security but constitutes a new global security model (Robles, 2016: 5). The need to take care of both privacy and security is based on the different transgressions that have occurred to these rights. These crimes about the misuse of the data of people, companies and service providers have led to having to be regulated at different levels. For example, at this time the use of mobile data of citizens held by teleoperators has been announced, to know their mobility by the National Institute of Statistics of Spain (INE) in exchange for the payment of an amount of money. This inappropriate use of data is being questioned by the administration and consumer associations that defend the rights of data protection according to existing legislation. Among this legislation is the General Data Protection Regulation of the European Union (EU), which declares in its Article 2, that its purpose is the protection of the fundamental rights and freedoms of natural persons and, in particular, their right to the protection of personal data.

Big Data And Privacy:

Data mining is demonstrating its effectiveness in different contexts, highlighting financial applications, commerce, private health and insurance, education, companies, etc. Data mining is conceived as a process of discovering new and significant relationships, patterns and trends when examining large amounts of data (Pérez and Santín, 2008: 1). Its roots are linked to Artificial Intelligence (in particular Machine learning) and Statistics (Aluja, 2001: 480). Its techniques and tools allow to establish decision-making processes, describe and better understand the data and predict future behaviors (Pérez and Santín, 2008: 2).

The health industry is generating data that is growing at an accelerated rate. This fact can improve health outcomes and reduce costs through Big Data, responding to the challenges of this data from efficient approaches and predictive models that could generate better predictions from them (Tan, Gao, Koch, 2015).

In the data produced in health care, the three data v are given, that is velocity, variety and volume (Zikopoulos, et al. 2011). These data are distributed among multiple health systems, insurers, researchers, government entities, etc. (Belle et al, 2015). The Spanish Society of Health Informatics, poses the opportunity of digital transformation for citizens and professionals as there is adequate technology and, most importantly, a huge amount of information in digital format that allows to increase scientific knowledge and make it immediately available to all healthcare

professionals in the healthcare network. And what is most important, this transformation will change the assistance relationship of end users with the system that serves them (Sampedro, 2019: 6), improving the benefits they receive thanks to the Digital Health History, electronic prescriptions, etc.

Health institutions, administration and other agencies involved must address security and privacy challenges, through Big data analysis software solutions with advanced encryption algorithms and pseudo-anonymization of personal data (Ristevski, & Chen, 2018: 4), so as to strengthen the encryption of the data and its cybersecurity. There are software solutions on the market to provide network-level security and authentication for all users involved, which can guarantee privacy and security, as well as establish good practices and governance standards (Ristevski, & Chen, 2018: 4).

The storage capacity of computers and other media are weak points in the face of people's privacy (Castillo, 2001: 38). The increase in crime and cyber conflict is the result of an explosive mixture of lack of political will, social unconsciousness and legal indolence (Robles, 2016: 34).

Privacy as opposed to the dissemination of personal data communication networks begins to be considered as one of the fundamental human values, which serves citizens to maintain their privacy, confidentiality and freedom. The right to the protection of personal data is carried out from a complex foundation, which can obstruct the scientific progress of humanity, so its importance for society must be considered and balance with other fundamental rights, in accordance with the principle of proportionality, provided that the security and privacy of people / patients are protected (Archenaa and Anita, 2015).

The protection of the privacy of people's data must be based on ethical behaviour of professionals and on legislation that protects the rights of privacy and privacy of people. The ethical ideas of protection of the privacy of citizens' data in a community must find their concrete expression in certain norms, laws and rules of conduct. These norms are the expression and recognition of the fundamental rights and obligations of man.

This protection must be in line with the care of the dignity of the person, placing the person at the center and seeking their well-being. This thought can be affected when the common good of a group of people or of society in general is sought, so it is necessary to establish measures that allow adaptation to the changes caused by technological advances on quality and ways of life (Beehive, 2017). It is based on the consideration that the use of new technological tools such as Big Data has placed us in a new paradigm of respect and recognition of confidentiality (Morente, 2019: 227). This means that the confidentiality and privacy of information about people must be answered, circumstances that modify the existing relationships in the healthcare context and there is a need to set limits on ethical behaviour that protect the privacy and security of citizen data

Digital Process Strategic Lines:

The use of Information and Communication Technologies (ICT) offers opportunities for people to live independently, while making it easier to perform the tasks of daily life, reinforcing cognitive health, and even they can receive health care and emotional support through them (European Commission, 2013). Currently they are conceived as one of the engines that can boost the economy and human development by improving health care. In the area of medicine, the advantages of the use of ICTs have been and are being truly relevant, being in the field of telemedicine where they acquire greater prominence (Hillán, Setián, Del Real, 2014: 121). Public policies are planned from the Council of Europe.

The European Digital Agenda set out to make Europe a hub for smart, sustainable and inclusive growth on the world stage. The Digital Agenda in Spain has facilitated the beginning of a Plan to implement the development of digital public services with the double objective:

1. Improve the quality and efficiency of public services through the use of ICT and thereby increase the economic and social growth of the country.
2. Take advantage of the momentum projects of modernization of public services for the development of the technology industry.

To achieve these goals, four axes were designed with their respective measures that are coordinated by the corresponding public administrations. These axes are:

1. Axis I: Health and Social Welfare Program to promote the use of ICT in the National Health System, in coordination with the Quality Plan of the National Health System and the National Chronicity Management Strategy, established frameworks by the Ministry of Health, Social Services and Equality.
2. Axis II: Digital Education Program, to strengthen the educational system through ICT.
3. Axis III: Digital Justice Administration Program. This axis aims to improve the Administration of Justice through ICT, in order to expedite and provide accessibility in the services provided by the Ministry of Justice.
4. Axis IV: Boosting the ICT sector through other projects to modernize public services that mobilize ICT demand.

These measures have the dual purpose of making public administration more efficient in the European context, while allowing a broad investment and development of ICTs in order to enhance the economic development existing in the sector. This development leads us to ask the following questions: What aspects are essential in the planning established in the European Digital Agenda? What changes entail the Axis indicated above in the relationship of citizenship with medical diagnosis and treatment? Is it necessary to use a professional ethic that puts ICT at the service of the person?

Ethics and big data:

In Kant's ethics, respect for the individual person as a self-determining being is among its principles, that is, the Kantian system tends to emphasize the individual person at the same time as their rights and duties, particularly the principles of freedom and justice. Faced with this consideration is utilitarianism that highlights the notion of public good, paying attention to the consequences of actions in relation to the principles of utility and justice (such as equitable treatment). Those people who intervene in the data through Big Data must keep a professional ethics and ethics that guides their activity towards the respect of the rights recognized in current legislation. These principles must be part of the "ethos" of society in general. It is necessary to differentiate between "ethics", "ethos", "morals" and "deontology":

The ethos refers to the dominant ethical conscience in a community, this conscience in a variable relationship with the form of behaviour, and which is expressed in all the norms that are considered in fact binding and that frequently entail the sanction of the law.

Ethics, on the contrary, is a much broader concept; it is the reflection on ethos, and it is not reduced to a description of the norms, but it tries to analyze which idea of man is at the base of his ethos.

Ethics is defined as the part of philosophy that deals with morals and the obligations of man. Other authors indicate that "ethics is the philosophical study of the foundations of good and bad behaviour and is, in essence, supra-social."

Morality deals with human actions, internal jurisdiction, personal or social behaviour, in terms of goodness or malice.

Deontology, is the term used to designate the duties that are imposed in a professional activity because of the nature of that activity. Deontological principles are those that dictate the rules of action necessary for the exercise of a profession, a profession that addresses man as a subject, where the object is not the subject and the end an economic product, but a service that puts in relation to One person with another considered for himself.

Ethics, morals and deontology, coincide in that they deal with the same object: the assessment of good and bad in human behaviour, emphasizing that their approaches are not totally equal. Ethics uses philosophical analysis, illuminates the problem from the angle of axiology, and through pure speculation tries to establish a duty of universal value. Morality studies human actions from an empirical, historical point of view, in the reality of different cultures. Deontology, fluctuating between ethics and morals and based on the conclusions of both, it is proposed to establish the specific rules that should govern behaviour in certain situations, such as the exercise of a profession.

Society now has a very dynamic vision of culture, always transforming itself despite how slowly it can do it. In it, values have no concrete and determined existence, which makes things have the value we place in them, the value that we hierarchically assign them. That hierarchy of values means that they are based on a greater or lesser convenience. The valuation has a specific character, in a given situation the object or thing valued and the subject it

values are involved. Values are the principles by which we are governed, which gives meaning to life. They are values of person and only in her they are. The value as an internal attitude is materialized externally in acts.

Ethics offers “some fundamental ethical keys that promote behaviours of respect, benevolence, justice and solidarity for all, especially laying down what could be the ethical foundations for the elderly” (García, 2003, p. 13). Especially the use of bioethical principles designed by Hellegers and disseminated by Gracia (2007), must be applied to establish a relationship between the principles from which bioethics starts (beneficence, non-maleficence, autonomy and justice) with the needs of people in solving the possible ethical dilemmas that may arise. These principles are related to values and needs that are systematized in the following table No. 1

Table 2:- Bioethical principles applied. Elaboration Munuera from García (2003).

APPLIED BIOETHICS PRINCIPLES			
ETHICAL PRINCIPLES	CONTENT	VALUES	NEEDS
Charity Principle	Do good to the elderly with a dignified and respectful treatment. And promote their good above any decision	It has dignity. It is a unique, irreplaceable and necessary being in this life.	Psychological needs: Maximize the benefits for the person and minimize the damages.
Principle of non-maleficence	Do not harm the elderly and avoid any possible evil (do not abuse, abandon or mistreat)	As a person, it maintains absolute value, with an end in itself.	Biological, and psychological, religious needs covered. Rights. Trust and sincere communication.
Principle of Autonomy	Respect the freedom and decision-making capacity of the elderly as a moral agent (both personally and surrogately)	You have freedom to decide for yourself.	Respect, acceptance and recognition as a person: respect for their rights and decisions
Principle of Justice	Equal consideration and respect for all, without any discrimination or marginalization, and guarantee the common good	Your safety must be taken care of	Equity in the distribution of charges and benefits. Intergenerational solidarity

Among the principles considered in the previous table, the principle of greatest benefit to the person stands out, due to the care that the professional places in not harming and intervening to obtain the greatest benefit. Certain authors establish the use of these “two fields of dialectical and conceptual debate: bioethics and law, in order to achieve the full dignity of the entire group and, by extension, of the whole society” (Palacios, and Romañach, 2007, p. 176-177).

Ethical problems can occur at any time where there is an attempt against dignity or respect for the person. Therefore and following Alvarado (2004), from the ethics of care that is based on the understanding of the world as a network of relationships in which we feel immersed, and from which arises a recognition of responsibility towards others (p. 31). Ethics will take care of and put the person at the center of all activity seeking the greatest good for society. The fundamental characteristic of care is the origin of life, the dignity of the same that entails in this respect and the search for well-being. Therefore, “human care is to help another grow, whatever that other, a person, an idea , an ideal ”(Quintero, 2001, p.18).

This action is special in professions that involve human relationships and constitute a service. In them their professional performance has an aspect that must be focused from the point of view of ethics because of the importance of their moral conduct. Obviously, in certain professions the validity of ethical principles is much more important than in others. Health professionals fulfill functions that concern individual intimacy and therefore need to

be performed with delicacy and high moral sense. Hence the importance of providing both scientific and technical training, with ethical training.

The use of ICT will allow a more efficient use of health expenditure in Spain. There are therefore sufficient reasons for the health sector to invest in technological security - for human and ethical reasons - while training personnel in cultures of compliance and awareness of the risks that new technologies may pose for patients.

Digital Health History And Electronic Recipe:

Public Administrations (AAPP) in Spain related to health act as responsible for the processing of personal data, and are governed by the new European Union Data Protection Regulation. This regulation recognizes the rights of citizens to maintain control of their personal data and guarantee high protection standards adapted to the digital environment throughout the EU for both judicial purposes. This provision regulates rights in relation to privacy and cybersecurity where Spain is slowly incorporated.

Digital development in healthcare in Spain can be measured by one of its indicators. The ERDF indicator (or Percentage of population covered by basic digital health services of the National Health Service), stands at 79, 2018, in 2018. This percentage of compliance exceeded the planned forecasts for this service, since it developed at 174.4% during the programmed years. The information by autonomous communities appears in the following table nº 2

Table 1:- ERDF Indicator 2018. Source National Observatory for Telecommunications and Information Society.

INDICADOR FEDER. Población cubierta por servicios básicos de sanidad digital del Servicio Nacional de Salud (SNS) (%)			
CCAA	Población cubierta por servicios básicos de sanidad digital del Servicio Nacional de Salud (SNS) (%)	Población identificada en el SNS (Población con Tarjeta Sanitaria Individual) a 31/12/2016	TOTAL POBLACIÓN CUBIERTA
ANDALUCÍA	87,7%	8.051.742	7.061.378
ARAGÓN	100,0%	1.297.398	1.297.398
ASTURIAS	36,2%	1.023.637	370.966
BALEARES	0,0%	1.091.230	0
CANARIAS	100,0%	1.988.367	1.988.367
CANTABRIA	100,0%	565.533	565.533
CASTILLA-LA MANCHA	100,0%	1.930.262	1.930.262
CASTILLA Y LEÓN	100,0%	2.340.690	2.340.690
CATALUÑA	100,0%	7.202.243	7.202.243
COMUNIDAD VALENCIANA	100,0%	4.661.607	4.661.607
EXTREMADURA	100,0%	1.047.817	1.047.817
GALICIA	100,0%	2.635.419	2.635.419
INGESA (Ceuta y Melilla)	0,0%	149.365	0
LA RIOJA	100,0%	309.220	309.220
MADRID	0,0%	6.493.103	0
MURCIA	100,0%	1.431.915	1.431.915
NAVARRA	100,0%	629.386	629.386
PAÍS VASCO	100,0%	2.193.341	2.193.341
TOTAL	79,2%	45.042.275	35.665.542
	% s/ Población total identificada en el SNS		79,2%

ERDF gives us information on two elements: access to the interoperable electronic prescription and the availability of medical records through the Internet that is done through a digital certificate in the SNS centers. These instruments and the treatment of the data they contain, have meant an improvement in the quality of care that patients receive. First, the electronic prescription has come to remotely monitor the treatment and management of chronic pathologies with the corresponding advantages for all the professionals involved. But especially for patients, since they do not have to constantly go to the consultations for this procedure, since it is resolved directly in the pharmacy.

Second, the Digital Health History (HDSqA), which has come to improve health outcomes and clinical trials (Castilla, 2019). This modality allows to work in a multidisciplinary team with the patient, through synchronous or asynchronous contact (Telemedicine), easily transmitted clinical information which facilitates the management and use of resources. For example, to discharge a patient who goes by ambulance to the hospital emergency room, access to his or her record avoids wasting time in the administrative process upon arrival to save his life, etc. . And especially an active patient with decision-making capacity and access to resources that help him maintain his health status (Patient Associations, App, wearables, etc.). These advances may lead to new multichannel interaction platforms for health professionals with citizens.

Other companies such as IBM have a cognitive computing technology (artificial intelligence), thanks to advances in Machine Learning Big Data, called Watson. Their responsiveness is allowing investigations to be more effective and can even achieve "the impossible" in less time. Watson is able to use cognitive systems and can make sense of 80% of the data that experts call "unstructured," such as videos, audios or images, which helps make better decisions supported by information. Watson's response capacity in social research can revolutionize existing practices in all areas given their proven effectiveness and profitability.

Data mining techniques allow to know the good practices that are carried out in most hospitals through the existing data in the EHR (Electronic Health Records), web, social networks, etc. (Dinov et al. 2016). Some authors have pointed out the potential of the analysis of data of different nature, such as social and scientific, to lead to new knowledge (Archenaa and Anita, 2015), which make it possible to identify new patterns in the behaviour and development of diseases. The World Health Organization (WHO, 2014), to compile its statistics uses many sources such as World Health Statistics, among which are public birth and death registration systems, hospital registries, household surveys, censuses, certified records of expenses, and data obtained from research projects.

Conclusions:-

The use of Big Data in the healthcare context is revolutionizing the healthcare relationship. The data analysis has come to configure a new relationship implementing the possibilities of diagnosis, and treatment. The advantages of its use allow to improve the diagnosis and treatment in certain diseases. Allowing prevention and avoiding in some cases its future appearance in other people. It is necessary to work in parallel in the generation of new knowledge about the mechanisms of diseases, and in the appropriate way to provide better treatment methods (Agarwal, Adhil, and Talukder 2015; He, Ge, He, 2017; Tan, Gao , Koch, 2015).

The necessary technical, economic and human resources must be put in place to guarantee the privacy and security of patient data in the healthcare context found in the patients' medical records. Data privacy can be achieved by giving instructions to the corresponding data processing software platform (Ristevski, & Chen, 2018).

The increase in the sophistication of cyber-attacks, with the consequent risk of data theft and attacks that block corporate websites, together with the new demands for accessibility of services (mobility, Open Data, etc.) are sufficient reasons for Use measures to avoid these facts.

Ethical training is necessary to build a computer ethics. People must be respected for the value granted to them as a human being of full values and have the means to establish the human rights approach in society. The ethics of care that must prevail in the use of Big Data will allow the opportunity to maintain life, giving rise to position itself against death and thus dispose of the mistreatment of everything that has life. Without forgetting that man lives and has always lived within a society provided with a moral code. Modern society tends to become an open society: the current moral code is no longer presented as untouchable but as susceptible to modification. The truly open society is pluralistic and therefore, a plurality of moral codes governs it.

The rights that citizens have in relation to the processing of their data must be disseminated and the violation of these rights must be claimed by the competent body. Each culture moves within a framework of concepts and practices, which change over time, so that the educational process in addition to selecting those that have a more lasting value, must help develop the ability to use new ones.

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