Revista Bioética
Print version ISSN 1983-8042 | On-line version ISSN 1983-8034

Rev. Bioét. vol.33 Brasília 2025

Confidentiality, intimacy and privacy in the context of human rights

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Abstract

The importance of confidentiality and intimacy can be found in both Hippocrates and the 2005 Universal Declaration on Bioethics and Human Rights and in other declarations, such as the 1947 Nuremberg Code or the 1948 Declaration of Human Rights, the 1964 Declaration of Helsinki, among others. The objective of this study is to analyze and deepen the notions of confidentiality and privacy as rights and obligations in the provider-patient relationship and determine their relation with the rules and principles. The conclusions associate these concepts to the notion of dignity in the Kantian sense as the ultimate foundation of the person, to be recognized as an end and not as a means.

Keywords: Confidentiality. Privacy. Human rights. Respect.

Resumo

Confidencialidade, intimidade e privacidade no contexto dos direitos humanos

A importância da confidencialidade e da intimidade pode ser encontrada tanto em Hipócrates quanto na Declaração Universal sobre Bioética e Direitos Humanos de 2005 e em outras declarações, como o Código de Nüremberg de 1947 ou a Declaração dos Direitos Humanos de 1948, a Declaração de Helsinque de 1964, entre outras. O objetivo deste trabalho é analisar e aprofundar as noções de confidencialidade e privacidade como direitos e obrigações na relação profissional-paciente e determinar sua relação com as regras e princípios. As conclusões vinculam esses conceitos com a noção de dignidade no sentido kantiano como fundamento último da pessoa a ser reconhecida como um fim e não como um meio.

Palavras-chave: Confidencialidade. Privacidade. Direitos humanos. Respeito.

Resumen

Confidencialidad, intimidad y privacidad en el contexto de los derechos humanos

La importancia de la confidencialidad y la intimidad pueden encontrarse tanto en Hipócrates como en la *Declaración Universal sobre Bioética y Derechos Humanos* de 2005 y demás declaraciones, tales como el *Código de Nüremberg* de 1947 o la *Declaración de los Derechos Humanos* de 1948, la *Declaración de Helsinki* de 1964, entre otras. El objetivo de este trabajo es analizar y profundizar las nociones de confidencialidad y de privacidad como derechos y obligaciones en la relación profesional-paciente y determinar su relación con las reglas y principios. Las conclusiones vinculan dichos conceptos con la noción de dignidad en el sentido kantiano como fundamento último de la persona a ser reconocida como un fin y no como un medio.

Palabras clave: Confidencialidad. Privacidad. Derechos humanos. Respeto.

Research

The author declares no conflict of interest.

Background

Currently, and according to a series of declarations, such as the *Declaration of Human Rights* (1948)[1], the *Universal Declaration on Bioethics and Human Rights* (2005)[2], the *Declaration of Alma-Ata* (1938)[3], the *Declaration of Caracas* (1990)[4], the Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care (1991)[5] and the Guiding Principles of Brasília (2005)[6], the clinical relationship is based on recognition of the dignity of the person and respect for patient autonomy. Health care providers would not be able to fulfill their mission if confidential information received were not protected by inviolable secrecy, which is necessary to protect fundamental rights of the individual, such as the right to respect for privacy.

The ethical foundation of professional confidentiality and secrecy is based on an assumed relationship of trust, in which a response of fidelity is expected. Accordingly, the professional secrecy duty is structured as the maximum expression of confidentiality as to patient-provided information, of one nature or another, and with no limit other than the possible damage to other people or to the good of the community.

Therefore, in the health sciences, particularly in mental health care, confidentiality and intimacy constitute rules and rights associated with all best practices within the scope of any treatment. Confidentiality refers to the limited use of clinical and social patient information. And privacy corresponds to the protection of self-image, fundamentally public, to which every individual is entitled and which constitutes, after a person's own life and health, the most precious asset of the individual, to which they have dedicated much of their efforts[7].

Objective

This study aims to analyze and deepen the notions of confidentiality and privacy as rights and obligations in the provider-patient relationship, and associate these concepts to the notion of dignity in the Kantian sense as the ultimate foundation of the person, to be recognized as an end and not a means.

To this end, we will adopt the following organization: first, we will analyze the notion of confidentiality and, next, that of intimacy. Both terms will be associated to compliance with rules or principles with the establishment of differences. Finally, the conclusions will provide an argumentative line about intimacy, privacy and confidentiality, and their relation with dignity.

Method

Qualitative methodology was used, focusing on the phenomenological-hermeneutic method for text analysis. Van Namen[8] makes this phenomenological-hermeneutic approach explicit by introducing semiotics: research in the humanities cannot be separated from the textual practice of writing. In a general sense, "qualitative research" is not just another category of research methods, but refers to a particular perspective related to the nature of the human sphere. And, within this methodology, phenomenological research is descriptive and qualitative, but also adopts a special type of problematization: the structures that produce meanings in textual reading and comprehension.

A literature review sought to trace all relevant publications related to the notions of dignity, intimacy, privacy and human rights based on the recommendations of the PRISMA-ScR statement[9]. The search was carried out from the beginning of the research until July 6, 2022, using the following terms: "confidentiality," "privacy," "intimacy," "rules and obligations," "human rights," "declarations," and "dignity."

Discussion

The duty of confidentiality

The term "confidentiality" derives from *fidelity* in the sense of duty to the other. As a quality of trust, it acquires the characteristic of expectation that the other will not betray expectations or projects. Hence the expression

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"breach of trust," which arises when someone misuses the information that, in a broad sense, they have of us or about us. The rule of confidentiality is directly related to the concept of professional secrecy.

Its moral foundations are associated with respect for the autonomy and intimacy of individuals. Information obtained in the provider-patient relationship is always considered confidential and guaranteed in the special, constitutional and legal scope. Only in exceptional cases can professional secrecy be breached and patient-provided information be revealed.

Each country establishes different statutes for this breach. To cite two examples, in Argentina, only in case of imminent risk, which may involve damage to oneself, damage to third parties or social risk that justifies this breach to avoid its occurrence. In Mexico, as per the Code of Ethics of Mexican Psychologists [10] (FENAPSIME), *information will only be disclosed with the consent of individuals or their legal representatives, except in specific circumstances where failure to do so would lead individuals or third parties to an evident harm, or except by express court order* [10].

The confidentiality rule affects the entire communication process. Bioethics has dealt extensively with confidentiality and privacy, especially in mental health care practice. For example, we note the Hippocratic Oath, which instructs physicians as follows: *And about whatever I may see or hear in treatment, or even without treatment, in the life of human beings, I will remain silent, holding such things to be unutterable* [11].

Thus, confidentiality or strict respect for patient privacy should be understood as a duty of the provider. It is the concept of secrecy in which all personal patient information belongs to them, is entrusted to the provider to whom he resorts for help and, therefore, is carefully kept confidential or hidden from third parties. Therefore, there is not only a theoretical moral justification for secrecy, but also a moral responsibility of each provider. The concrete fact is that the patient—implicitly but really—trusts that the intimate details of their life will not be revealed. If the provider fails, they will have severely betrayed the trust of a person in a vulnerable state [12].

Based on the principles of bioethics, the recognition of autonomy is the foundation of respect for privacy. Regarding the ethical approaches of maximum and minimum ethical duties, the private sphere falls within the scope of the maximum ethical duties that must be respected provided that the minimum ethical duties are not violated. Therefore, just as every right is recognized as having certain limits, the right to privacy cannot be considered absolute.

The limits to autonomy are in the principles of justice and non-maleficence, which are minimum ethical duties [13]. Based on these bioethical principles, there may be exceptions to the duty of confidentiality for reasons of common good, to avoid risks to third parties or to protect the individual from further harm. This means that, in principle, it is mandatorily absolute; but, depending on the case, it is teleologically relative. The relativity on the breach of professional secrecy arises from situations in which the patient's well-being conflicts with the duty to avoid harm to third parties or oneself. These are exceptions that the provider must duly justify in each case.

Several arguments have been used to support the rule of confidentiality. These include: 1) Consequentialist arguments: it is argued that trust in clinical relationships is essential in order to provide reasonable care; as a result, breach of confidentiality would cause patients not to trust on data and circumstances that are elementary to establish accurate diagnoses, correct indications and accurate prognoses. 2) Arguments derived from the principle of autonomy and intimacy: refer to the person's right to have their privacy respected. 3) Arguments based on fidelity: It is understood that a promise offered explicitly or implicitly must correspond to the patient's reasonable expectations of intimacy [14].

From another perspective on the duty of confidentiality, two distinctive lines can be drawn: that of deontological theories and that of utilitarian theories. In relation to the first, confidentiality is based on the principle of autonomy, according to which every human person is free and has the right

to make decisions about their life and is responsible for them. Confidentiality is an instrumental value of this principle, since it constitutes a guarantee against the intrusion of third parties into personal intimacy [15]. From the consequentialist perspective, it would be impossible for a treatment to be recommendable in case of suspicion as to the secrecy of what is mentioned therein. The fear of information disclosure would lead the patient to keep reservations about what they are reporting, which would lead to the failure of any proposed beneficial attempt.

The right to intimacy

The term "intimacy" comes from *intimus*, which is the inner aspect that each person has or possesses, and originally was applied more to the religious or moral area. Currently, more broadly, it refers to the immediate surroundings of the individual, to what was freely withheld by the person in case of possible intrusion by others. Intimacy is the inner aspect that only each person knows about themselves. According to Beca [16], it is the maximum degree of immanence, that is, that which is kept inside.

While the concept of privacy includes the right to protect one's personal life from any intrusion. However, in practice, both terms can be understood as synonymous. The private or intimate sphere presupposes that the individual is recognized as a person and has their attributes, specifically self-awareness and ability to exercise their freedom. Intimacy is a constitutive part of the human person and also acquires importance for psychological development and personal maturity as necessary conditions for every interpersonal relationship.

Thus, intimacy or privacy constitutes a primary need and a fundamental right of the individual. The right to privacy as a condition of the person is of such relevance that, like other fundamental rights, it has historically been explicitly recognized in the *Universal Declaration of Human Rights: No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation. Everyone has the right to the protection of the law against such interference or attacks* [1]. Thus, every person, for the simple fact of being a person, has the right to honor and dignity recognized. This is the basis of several privacy protection laws in force in most countries, which go beyond the protection of private property [10].

Individuals have the right to decide for themselves the extent to which they will share with others their thoughts, feelings, and private life facts. Intimacy should not be limited to not being disturbed, not being known in some aspects by others, but rather include the right to control others' use of information pertaining to a particular subject. Intimacy is the reserved sphere, free from interference, that involves the individual.

Human dignity, in the social sphere, is guaranteed to the extent that it is possible to preserve one's own privacy, understood as that inner aspect that can only concern the human being as an individual or within a restricted context of people, ultimately determined by consent.

According to Olano García [17], intimacy is a right that is projected in two dimensions: secrecy of private life and individual freedom. As secrecy, all illegitimate disclosures of facts pertinent to private or family life, or equally illegitimate investigations of facts proper to private life, are against it. As individual freedom, it transcends and materializes in each person's right to make decisions for themself that concern the sphere of their private life. Violations against intimacy can originate from both individuals and the State. Hence the importance of protecting intimacy as a means to ensure the tranquility necessary for the physical, intellectual and moral development of people, that is, as a right of the personality [7].

Differences between intimacy and confidentiality

The concept of privacy is often associated to synonyms such as intimacy, private life and, in some cases, confidentiality in the sense of private. It is a fact that the Spanish language distinguishes between the adjectives "private" and "intimate"; therefore, it is not surprising that this distinction has recently been extended to nouns. The adjective "intimate" means "relative to the depths of the soul" (intimate feelings, intimate conviction), "reserved" (intimate ceremony, intimate body parts) or "relative to a close

relationship" (intimate friend; sexual relations are by antonomasia intimate relations); in the plural form, it is used to designate the closest family members and friends (the intimate ones) [1].

In turn, the term "private" has the following meanings: "private, personal" (private life, private meeting, private area, private use, private access); "related to what is done in solitude or in the sight of a few" (in private); and "private, non-State property" (private sector, private property, private school, private medical care, private television, etc.).

The meaning "in private" has a less reserved tone than the phrase "in intimacy," which implies a higher degree of isolation and the idea of greater use and enjoyment of solitude or the company of a few close people. Therefore, private and intimate do not seem synonymous. Intimate applies to the deep things of the human soul, as well as to what is close, while private refers to what is personal and particular, that is, what is kept distant from the public and that must be free from intrusion.

Thus, an intimate meeting is a very close meeting, in which there is great affective closeness, while a private meeting is a meeting distant from the public, or a meeting to discuss private matters [18].

Privacy, in turn, is the sphere of the person, composed of their family life, their hobbies, their private assets and their personal activities, separated from their professional or public life. All these aspects, in addition to the intimate ones, constitute a sphere of life that one has the right to protect from intrusion. As observed, the sphere of intimacy is part of privacy, but not the other way around. Both intimacy and privacy are reserved, but differently.

For intimate matters, there are people who are reserved even with those closest to them, as these matters are in their deepest inner self, while privacy is preserved from the gaze of those who are not part of their personal circle, consisting of family members and, in some cases, personal friends. These belong to private life, but only a few are intimate.

The concepts of privacy and confidentiality are related; however, they are not the same thing. Privacy refers to the individual or subject, while confidentiality refers to the actions of the provider. In this sense, confidentiality is associated with the treatment of information that an individual expects not to be disclosed without their permission. In this sense, privacy as a right can be violated, while confidentiality as an agreement can be breached.

Although the confidentiality rule is related to the right to privacy, it is not exactly identical [16]. From the right to intimacy arises confidentiality as a value and as an attribute of the information that contains personal data. Within the scope of the ethics discipline, there is usually a distinction between what is legal and what is legitimate, requiring ethical legitimacy from all legal regulations. In addition, it is argued that people should act correctly out of moral conviction and not out of fear of punishment for transgressing a legal rule.

In the field of mental health care, confidentiality is legally correlated with professional secrecy. However, it is not always respected, and its non-compliance is justified by the promotion of certain activities, undoubtedly valuable, such as professional education or research. This indicates an area of imprecise boundaries between individual rights and the rights of society, a field that is historically conflictual and marked by contrary ideologies and opposing theses on the theory of the state. The current trend—both in the legal and bioethical spheres—is to prioritize the rights of patients and persons in general [19].

Are confidentiality and privacy rules or principles?

Declarations of "principles" constitute, in fact, one of the most distinctive activities of the discipline of bioethics.

On many occasions, these declarations are ratifications of principles proposed prior to the constitution of bioethics as a discipline, such as the *Nuremberg Code* [19] or *Universal Declaration of Human Rights* [1] in 1948; the *Declaration of Helsinki* [20] of 1964; and *the UNESCO Universal Declaration on the Human Genome and Human Rights* [21] of 1997. Three principles included in the Belmont Report [22] also acquired a special meaning proposed by the United States Congressional

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Committee: the *principle of autonomy*, *the principle of beneficence* and the *principle of justice*. Along with these principles, other proposals added the *principle of non-maleficence*; as is the case of the proposal of Beauchamp, who was a member of the Belmont Commission, and of Childress, in *Principles of biomedical ethics* [23].

A principle is a judgment of the duty type, *an ought-statement*, which can express or hold a command over a precept or a description of a conduct, to be adopted or avoided. A rule is a guide extrinsic to the standard and is used for the interpretation and application of a normative principle in practice. The principles, with regard to the rules, maintain the relation from the most general to the least general and, at the limit, to the particular case.

In view of the above, principles as fundamental refer to terms, relations and operations, in a dynamic field, established as a global system of interactions in which the parties that manage it cannot be distinguished. The rules, on the other hand, correspond to the operating subjects as they are assigned the function of intervention, as parties, in the management of the system, in the face of parties that tend to deviate from its principles or even oppose them. The managers to whom the rules refer are health care managers (psychologists, physicians, politicians, legislators).

Following this line of argument, confidentiality is a rule that health care providers are obliged to comply with, with certain exceptions in each case. While privacy is a principle that, in its fundamental form, expresses the recognition of autonomy and intimacy and constitutes the basis on which professional practice and its obligations are guided. Both terms are associated with a cause-consequence relation at two different levels. Being the person deserving of respect, they are not an object of exchange, but an end in themself, self-determined; their intimate sphere *must* be protected by those who provide them with health care in a situation of trust.

Final considerations

The notion of human dignity as a personal attribute that makes the person deserving of respect beyond their actions, as well as the intrinsic value of the person as an end in themself, capable of setting goals, becomes an inescapable value that is the foundation of each subject's freedom and autonomy.

Kant [24] advocated the importance of rights in explaining the difference between things and people. According to the author, there is a clear distinction between *value* and *dignity*. Dignity, as an intrinsic value of the moral person, admits of no equivalents; dignity should not be confused with anything, with any commodity, since it is not something useful, exchangeable or profitable. That which can be exchanged and replaced has no dignity, but rather price [24].

Human dignity is a fundamental and unalterable value. Although it can be interpreted differently by individuals, its foundation lies in the fact that every being with the capacity to reason and decide is entitled to it, that is, every human being is entitled to it. Dignity—along along with it the right that one's own life be intimate and protected by professional secrecy—nullifies any distinction that threatens the free exercise of self-determination and the volitional possibility of one's own ends. Dignity—as essence of the human existence—enables personal fulfillment in all aspects.

Most declarations about mental health recognize it as a process determined by historical, socioeconomic, cultural, biological and psychological components, whose preservation and improvement involve a dynamics of social construction associated with the effective exercise of the human and social rights of each person. It is the recognition that every subject, for being a person, has as a principle the moral recognition of the community to which they belong, as established by Habermas [25] and determines that human dignity is not just a classificatory expression, as if it were an empty substitution parameter that groups multiple different phenomena. On the contrary, it constitutes the moral "source" from which all fundamental rights derive their support [25]. Dignity is the reflection of the fundamental principle of determining the course of one's own ends [24].

Precisely, the idea of "process" underscores the dynamic nature of rights, whose exercise depends not only on mental health care service

users, but also on the society to which they belong and the providers who participate in the treatment. This is how social and human rights issues are involved: citizens suffering from mental health illness have the right to receive health care, but this health care process must not violate their autonomy, their intimacy, the possibility of preserving social and family bonds, which must also be promoted for the best recovery of the patient.

This double reading—of the recognition of the community of moral beings and the inherent condition proper of the person as distinct from the thing—indicates how users in the field of mental health receive their care. There may be extreme temporary conditions where capacity is diminished, but that same scenario can never diminish dignity. While intellectual capacities may suffer some form of limitation, dignity can never be understood in terms of diminution. In this sense, it is not quantifiable or assessable through any test, questionnaire or exam.

However, dignity is the foundation of every treatment as a process of good life and, above all, own life. Is it possible to measure it? Respect for dignity and, with it, the requirement that privacy be respected and that it be possible to decide what information will be disclosed, becomes relevant in the field of mental health. The foundation of dignity is at the core of all mental health treatment and is manifested in the recognition of privacy and intimacy. This change has profound consequences.

An ill person carries a semantic connotation that undermines equality and freedom. The user is a subject of law who uses what is best for themself in order to promote their quality of life. It is no longer the healthy-ill tension, but rather the user-health care service tension. This change is only conceivable to the extent that the dignity of each individual is recognized and that the community, both in the strict sense of the mental health community and in the broader social and democratic sense, is a fundamental part of the implementation and unwavering respect for this exercise. Respect for vulnerability, the promise that information provision is based on a relationship of trust, is not a mere instrument, but the primary manifestation that every user will be recognized as a subject of law. Thus, health care is possible.

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Editor in charge: Dilza Teresinha Ambrós Ribeiro

Received: 5.21.2024
Revised: 1.28.2025
Approved: 2.11.2025