



Patient Complaint Systems from the Perspective of Healthcare Bioethics

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Abstract

This article aims to analyze the complaint systems from the unique and crucial perspective of Healthcare Bioethics, a new theoretical branch of Clinical Bioethics developed in Latin America, in the Post-graduate Program in Bioethics of the University of Brasilia. Healthcare Bioethics, with its four main axes: Patients' Rights, patient centrality, the partnership relationship between the actors in the clinical encounter, and clinical empathy, provides a comprehensive and ethical lens through which to view healthcare issues. Complaints in healthcare, considered complex narratives that reveal important information about the organization and exert important impacts on healthcare and the clinical relationship, are no exception. The methodological approach is theoretical and documental. The basis for the theoretical framework adopted by Healthcare Bioethics were the studies by Albuquerque and Albuquerque and Tanure, since they are precursors in Brazil to the research developed on the subject. The conclusions drawn are that organizations need to have complaint systems based on Healthcare Bioethics to contribute to the patients and their families feeling welcomed and recognizing patient centrality concerning the complaints presented. Finally, it is necessary to highlight the scarcity of studies that draw on this new paradigm of healthcare applied to the analysis of patient complaints.

Keywords: Bioethics; Patients' Rights; Complaints; Human Rights; Patients

Abbreviations

UDBHR: Universal Declaration of Bioethics and Human Rights; PCC: Patient-Centered Care; SDM: Shared Decision-Making.

Introduction

Complaints in healthcare are complex narratives that report perceived failures in healthcare delivery or rights violations from the perspective of patients and their family

members. Unlike other mechanisms, such as satisfaction surveys based on the logic of consumption, patient complaints present specific issues about healthcare, including those related to areas where monitoring may be more challenging to perform, for example, on matters related to the provision of unfinished or omitted care and on the continuity of care, either among the professionals themselves or when the patient is discharged. Complaints are also understood as an essential resource for obtaining information about the health organization, improving care and patient safety and experience, therefore involving micro and macro issues

related to healthcare. It is shown that some patients may be afraid of being stigmatized as “difficult patients” as a result of the complaint presented, and they worry about possible repercussions of the complaints on their clinical treatment. The discussion and further development regarding the right that every patient has to complain when their rights are violated, which has resulted in the development of complaint systems, originated in the mid-1970s, simultaneously with the recognition of patients’ rights and the understanding of the patient as a subject of rights, no longer as an object of care. It should be noted that complaint systems derive from the patient’s right to file a complaint, which includes the existence of systems specifically created to deal with complaints in healthcare, and these systems are fast, free, and centered on the needs of patients. Thus, the general objective of this work is to analyze the patient complaint systems from the perspective of the Bioethics of Healthcare, a new theoretical branch of Clinical Bioethics, based on Article 3 of the Universal Declaration of Bioethics and Human Rights (UDBHR), which recognizes the role of the patient in their care, including concerning complaints. It is essential to highlight the scarcity of studies that draw on this new paradigm of healthcare applied to the analysis of patient complaints. The methodological approach is theoretical and documental. It is noted that the theoretical framework of Healthcare Bioethics, as a branch of Clinical Bioethics, is under development and is based on investigations in the field of Patients’ Rights and, consequently, in human rights applied to healthcare. The theoretical framework adopted was based on the studies of Albuquerque and Tanure on Healthcare Bioethics since they are precursors in Brazil to the research developed on the subject. The studies by Sundler, Darcy, and Raberus were used as a reference for complaint systems since these authors analyze patient complaints using a human rights framework. Other sources were investigations by Van Dael et al., which analyze complaints in healthcare, and by Gallagher, Mazor, and Kathleen, who address the functions of complaint systems. In addition, a theoretical search was undertaken at the international level to understand the practice related to complaint systems present in several countries. The Final Report of the European Union on Patients’ Rights was considered for documentary research, providing a cross-sectional view of the situation of patients’ rights in the thirty countries studied. The Report indicates that there is a set of patients’ rights that are extracted from European legislation and are incorporated into the list of rights applicable to patients in the context of healthcare, among them the right to complain, addressed in this study and directly related to the existence of complaint systems. Therefore, this work is structured in five chapters:

1. Healthcare Bioethics and Complaint Systems
2. Patients’ Rights and Complaint Systems
3. Patient Centrality and Complaint Systems
4. The Partnership between the Actors in the Clinical

- Encounter and Complaint Systems
5. Clinical Empathy and Complaint Systems.

Healthcare Bioethics and Complaint Systems

Clinical Bioethics is a field of bioethics, whose scope is to provide ethical tools to deal with moral issues that emerge from healthcare, not only dealing with the reflective or descriptive field but also understanding its prescriptive action, taking into account that it is Applied Ethics [1]. Therefore, the role of Clinical Bioethics encompasses the theoretical approach and the practical solution to the moral dilemma, making it possible to identify and analyze concepts and arguments involved in clinical practice [2]. Thus, this type of Bioethics encompasses conflicts that permeate everyday situations in healthcare relationships, including clinical encounters and complaints arising from clinical practice and patient experience within the health system [3]. Consequently, it is not appropriate for Clinical Bioethics to develop separately from the context of health organizations, at the risk of ignoring the reality experienced by patients and their families and the violations of rights in these environments, including the ethical repercussions on healthcare [3].

The Principlist Bioethical Theory, elaborated by Beauchamp and Childress, is the hegemonic theory in the world, and it recognizes the existence of four principles:

1. Respect for autonomy
2. Beneficence
3. Non-maleficence
4. Justice [4].

These principles were developed to guide the decision-making process of researchers and health professionals in biomedicine. They were conceived as universal and used as a simplified instrument for conflict analysis in the bioethical field [5]. In healthcare, this theory provides epistemic privilege to health professionals and does not recognize the existence of power asymmetry in the relationship between patients and health professionals. In addition, it deals with bioethical dilemmas from the perspective of health professionals instead of recognizing the role of the patient and the human rights of patients are equivalent in value to the obligations imposed on health professionals [6]. Even though the perspective addressed in this research was not developed by Beauchamp and Childress, it is necessary to highlight the historical importance of studies on Principlism for the development of Bioethics and for research resulting from these studies.

It should be noted that, regarding studies on complaints from patients and their family members, there is not

enough research that applies the bioethical framework of human rights to health and this new bioethical paradigm, hence the importance of this article. In Latin America, a new bioethical theoretical framework has been developed and is called Healthcare Bioethics. The Graduate Program in Bioethics of the University of Brasilia develops research on this new aspect of Clinical Bioethics based on human rights. Healthcare Bioethics is based on Article 3 of the UDBHR, which establishes that “human dignity, human rights, and fundamental freedoms must be respected in their entirety” [3] and on the new paradigm of healthcare, whose denomination is the “Patient Revolution” and is understood as a social, scientific, sanitary, cultural, ethical and legal movement that originated in the 21st century. This movement recognizes patients as protagonists of their care and no longer as objects of intervention and procedures. In this sense, Healthcare Bioethics focuses on persistent issues addressed by patients and their families, which are often not considered, given that they are not always given a voice [3].

The theoretical framework of Healthcare Bioethics has a dual nature: one is substantial ethics, which “considers the purpose or goods that are aspired to ethically evaluate practices, aiming at the creation or strengthening of bonds of social cohesion,” and the other is procedural ethics, in which a proper procedure is proposed for ethical deliberation to take place [3]. Thus, Healthcare Bioethics comprises four axes:

- a. Patients’ Rights
- b. Patient centrality
- c. The partnership relationship between the actors in the clinical encounter
- d. Clinical empathy.

Unlike other mechanisms, such as satisfaction surveys based on the logic of consumption, patient and family complaints are a valuable source of information and present specific issues about healthcare, including those related to areas whose monitoring may be more challenging to perform, for example, issues related to the provision of unfinished or omitted care and on the continuity of care, either among the professionals themselves or when the patient is discharged [7]. Complaint systems explicitly created for the context of healthcare are of paramount importance, and, as well as the clinical encounter, the resolution of complaints must be based on the new paradigm of patient protagonism [8,9].

We analyze each of the axes of Healthcare Bioethics and their corresponding application to complaint systems.

Patients’ Rights and Complaint Systems

The first axis of Healthcare Bioethics to be addressed is Patients’ Rights, which is understood as a new legal

branch that deals with legislation, theory, and jurisprudence concerning norms on patients’ rights and implementation mechanisms. The recognition of patients as subjects of rights dates back to the 1970s and was influenced by feminist movements, corroborated by the activism of institutionalized psychiatric patients and the movement for consumer protection [9]. According to Albuquerque, these social movements brought about the recognition of the ethical-legal obligation to impose respect for the patient’s self-determination. In the early nineties, several countries developed specific legislation recognizing the existence of patients’ rights [9]. Finland was the first country to adopt a law on the subject. Subsequently, countries such as the United States of America, Argentina, The Netherlands, and Ecuador also drafted their statutes. In Europe, the Declaration on the Promotion of Patients’ Rights was based on applying human rights in the healthcare context. Thus, since 2000, there has been a deepening of the Patient-Centered Care (PCC) and the Shared Decision-Making (SDM) models, as opposed to the paternalistic model. Thus, the patients’ role as protagonists of their care was recognized by disseminating patients’ rights.

It is necessary to distinguish patients’ rights from those of users and consumers [9]. Users’ rights are those that individuals have concerning health services and are linked to the provision of services by the State, which involve access to health goods and services, for example, the claim to have access to medication. Thus, it is based on Health Law. In contrast, consumer rights in the context of healthcare are those that people have when they are in the position of a consumer, fulfilling the rights provided for in the Consumer Protection Code and assuming a consumer relationship with the health professional or service based on Consumer Law, guided by the logic of consumption and reducing care to a patrimonial relationship. Patients’ rights apply to individuals in a healthcare relationship, whether in a public or private health facility. The foundation is in human rights and is based on the logic of care, recognizing the relationship between the health professional and the patient as one that can be (re) modeled at all times and based on trust and the guarantee of patient dignity [9].

Thus, patients’ rights establish moral minimums in healthcare since they are based on human rights and are anchored in the inherent dignity of all patients. In this sense, patients’ experience is construed as essential knowledge about their bodies and unique life experiences that differentiate them from other patients, even if they have the same diagnosis [6,9]. The recognized rights of patients [9] are among these: the right to quality and safe healthcare; the right to self-determination; the right to refuse treatment and procedures; the right to informed consent; the right to participate in the decision-making process; the right to

a second opinion; the right to confidentiality of personal data; the right not to be discriminated against; the right to information about their health condition; the right to access medical records; the right to file a complaint, and the right to full reparation.

Generally speaking, there is no way to separate the complaint systems from the patient's rights since they are directly related. Article 13 of the European Charter of Patients' Rights provides for the right to file a complaint, establishing that health services must guarantee this right whenever the patient has suffered an injury, with the consequent guarantee of the right to receive a response [10]. In addition, the final report of the European Union on patients' rights provides mechanisms to investigate and respond to complaints submitted by patients [11]. Thus, when patients' rights are violated, or when something unexpected occurs in their healthcare, the patient and their family members have the right to file a complaint, and, usually, the complaints are a means to seek explanations and some information about what happened [9].

Research shows that patients and their family members are more likely to file a complaint if they are knowledgeable about their rights and can easily access information describing the procedure intended for that purpose [12], which indicates the importance for States to have disclosure about the existence of the complaint system and the means for their complaint to be filed. In this sense, one way to verify how patients' rights are addressed in health systems practice is to analyze the content of patient complaints. It is noted that the number of complaints filed by patients and their families, albeit increasing, is considered only "the tip of the iceberg" since several patients have never presented formal complaints. Therefore, these have not been counted.

It is pointed out that patients' rights are formally recognized, emphasizing the existence of a specific law, which contributes to the increase in complaints in healthcare, given that there is a change in people's attitude towards the procedure for filing complaints [13]. Thus, it is essential to recognize a right that ensures patients and their families the possibility of lodging complaints, with consequent reception and information. It can contribute to more patients reporting rights violations and showing their dissatisfaction when something does not happen as expected within the scope of healthcare.

The second element of Healthcare Bioethics and its consequent application to complaints systems will be described next.

Patient Centrality and Complaint Systems

In the context of healthcare, when a complaint is presented by the patient or a family member, the patient is expected to receive the necessary care according to their needs. As seen in practice, the Principlism does not recognize the patient's role as the protagonist of their care [14]. However, Healthcare Bioethics is based on identifying the patient at the center of their care and complaints since it must also be guided by patient centrality. Thus, a response to the complaint that is centered on the patient implies that the resolution be presented to the patient or their family in an individualized way and containing some essential elements, such as the explanation of what has happened and learning from this, along with the indication of what conduct has been or will be adopted [7].

In addition, the patients' or their family's satisfaction concerning the resolution of the complaint is associated with a formal response by the health organization. For this to occur, health professionals must provide detailed information to the professionals of the complaint system, which requires the organization's action to encourage professionals to report fully what has happened that gave rise to the complaint [15]. Furthermore, research reports that professionals whose work is to receive complaints are not always equipped with the communication and empathy skills necessary to provide satisfactory answers to patients and their families, which suggests the need for training to act according to a patient-centered approach [7].

Thus, considering the commands extracted from the PCC [16], which are:

A. sharing of power and control between the professional and the patient
 B. respect for patients as unique beings, with an obligation to provide care according to their terms
 C. active listening to the patient, understanding the environment in which they live
 D. prevalence of the patient's life goals, when compared with those of the health professional [16], the complaint system should be able to understand the needs of patients and their family members who present the complaint, taking into account that each situation experienced, as well as each patient, is unique and that their emotional, psychological and social needs are also reflected as unique and should be recognized by the organization. Therefore, it is essential to listen attentively and empathetically, giving voice to the patient and their report from their perspective of the situation experienced [17]. Moreover, the patient should be asked what they expect from the presentation of the complaint, including their active

participation to categorize the severity of the situation, for example, from insignificant to extreme and, as for the probability of occurrence, from almost specific to rare [18]. In this way, complaint systems should be centered on the patient, not the health organization.

As a rule, organizations tend to focus on the needs of doctors and other professionals, not on patients. Knowing about diagnosis and treatment is not the same as understanding what it is like to be sick [19]. Thus, patients carry their life experiences with them, not only the experience of the disease in their body but also the knowledge regarding the functioning of the healthcare system. Research has confirmed that patients are frequently the only ones who can evaluate various aspects of the care provided and its quality. However, patients and their family members fear their recommendations will be ignored. In contrast, multiple professionals tend to assume that patients have nothing to add to their suggestions and complaints [19]. Thus, it is concluded that complaint systems have the ethical command of PCC and communication, which must also be patient-centered, without interruptions, and accept what is presented.

Partnership Relationship between Clinical Encounter Actors and Complaint Systems

As can be seen from Healthcare Bioethics, the existence of asymmetry of power in the relationship between health professionals and patients is recognized, and based on this awareness, reflections are proposed to modify the clinical practice [14]. The partnership between the actors is related to the asymmetry of power between patients and health professionals. Research conducted in Ireland in 2019 and 2020 identified issues related to the asymmetry of power in the relationship between patients and health professionals as barriers to filing complaints [20]. It is interesting to point out that in this research, the doctors and nurses highlighted the power imbalance in the relationship, considering that patients would hesitate to challenge the professionals through complaints. The stigma of “complainer” or “troublemaker,” the adverse reaction that the patient feels, and the concern about whether the complaint will affect current and future care are considered barriers to filing complaints, especially in cases of long-term care relationships. Similarly, patients at a disadvantage may feel even less empowered to complain [21]. Thus, it is perceived that power asymmetry can negatively impact the presentation of complaints and become a barrier to their occurrence.

Thus, the empowerment of patients, resulting from a cultural change of this relationship constantly seen as asymmetric, is considered a facilitator for presenting complaints by patients [20]. In this sense, encouragement and

information regarding the existence of complaint procedures provided by professionals and employees of organizations reduce the anxiety and stigma that prevent patients and their families from filing a complaint [7]. Ideally, the aim is to resolve the complaint in the health organization through the complaint systems so that the relationship between clinical actors is preserved and, when possible, improved. Therefore, focusing on issues beyond the individual fault of the professional involved in the complaint can help deal with these situations and benefit the professional, who may even need different types of support [21].

Although it is not the focus of this article to highlight issues involving the interpersonal relationship between health professionals within a team, it is essential to note that the existence of power asymmetry in this relationship also influences the presentation of complaints by patients since barriers may arise when the health team only converses with similar professionals, creating a vertical communication, with a potential demonstration of inequalities which can negatively affect patient-oriented healthcare [22]. Similarly, the barriers identified in the communication between professionals also affected organizations' ability to foster a favorable policy aimed at learning from patient complaints. Research also indicated that if the person responsible for training and learning through the complaints presented by patients is considered as “lower” in the professional hierarchy or has little clinical credibility, for example, for being from an area other than health or being junior in the professional hierarchy, the communication may not be constructive. Thus, this information consolidates how negative power asymmetry is in all relationships that permeate the healthcare context, not restricted only to the relationship between health professionals and patients. In contrast, the partnership relationship between the actors in the clinical encounter triggers positive reflections in the context of complaints in healthcare, and it is therefore essential that the partnership between them is fostered and recognized [20].

Clinical Empathy and Complaint Systems

The fourth axis of Healthcare Bioethics is clinical empathy, which relates directly to patient complaint systems. Empathy in the context of the capacity of health professionals is understood as clinical empathy. According to Albuquerque [1], the development of a relationship between the health professional and the patient depends on the professional's ability to establish an empathic understanding of the situation experienced by the patient. In this sense, its triple composition is pointed to as a consensus: 1. Understanding 2. Communication and 3. A therapeutic action based on the result of understanding and communication. Thus, clinical empathy is conceptualized as a multidimensional capacity

composed of two dimensions: “a cognitive one, in which the professional understands the patient’s perspective, and an emotional one, through which the professional tunes in to the patient’s emotions.” Understood as one of the elements of Healthcare Bioethics, clinical empathy is an approach to Clinical Bioethics that promotes patient empowerment, recognizes them in all dimensions, and is committed to what matters to the patient, contrary to the Principlism, as discussed above [1]. In addition, it is confirmed that, from the perspective of Healthcare Bioethics, the patient is the protagonist of care, and clinical empathy contributes to the construction of trust, adherence to treatment, and mutual understanding between the actors of the clinical encounter [22].

In the United Kingdom, communication was rated as one of the leading causes of complaints. Patients’ statements are recurrently understood as “irrelevant, confused, very emotional and useless or a ‘waste of time’” directly related to epistemic injustice. The privilege often given to training and technical aspects inherent to professional practice, as opposed to knowledge rooted in patient experience, encourages health systems to propagate knowledge asymmetries [22].

Epistemic injustice is found concerning patients since the resources necessary to understand social experiences are not accepted as part of the dominant hermeneutic resources [23]. Thus, in healthcare, patients who are not encouraged to speak freely about their history may have difficulty participating in institutional mechanisms that promote their participation since filing complaints is one of the mechanisms of patient involvement in their care. In addition to the clinical encounter, the fact that health professionals are identified as epistemically privileged contributes to their choice to confer credibility or not to the patient and their speech. Considering that the relationship between health professionals and patients is conducive to entailing epistemic injustice [1], it is essential to relate this concept to complaints in healthcare.

Therefore, reflecting on the constitution of a complaint system based on clinical empathy is essential, with the application of active listening and training programs for professionals [24]. By providing healthcare professionals with the necessary tools, they can communicate empathetically with patients. Active listening to complaints is essential since patients and their family members express their concerns in their complaints, and it is necessary to have a safe environment that supports them now. Research conducted in Sweden has indicated that 77% of the complaints were attributed to the lack of empathy from health professionals [25]. In the same sense, research in the United Kingdom has

shown that 82% of patients would hardly complain if their doctor communicated with them openly and emphatically [26]. Thus, demonstrating empathy is essential when unexpected results occur in healthcare. There may be an apology ready: “This is not the result that any of us wanted or predicted.”

Thus, clinical empathy associated with the right to complain, and consequently to Healthcare Bioethics, is vital to increasingly recognize patients’ protagonism and voices, even when complaints are presented. As examined, complaints contain significant reports, not only about individual patient care but about the entire health system in which patients are inserted. Thus, clinical empathy is paramount in health since it plays a role in clinically improving patient treatment and promotes the satisfaction and well-being of patients and health professionals [27], which relates to the filing of complaints.

Conclusion

The complaints presented by patients and their families are understood as complex narratives that report failures in care or rights violations from their perspective. They are a valuable source of information on issues related to the organization, the care provided, and patient safety and experience. Thus, it is crucial to have complaint systems that welcome and resolve complaints presented by patients and their family members in the context of healthcare. As seen, Healthcare Bioethics, as a new approach to Clinical Bioethics developed in the Graduate Program in Bioethics of the University of Brasilia, has four axes: 1. Patients’ Rights 2. Patient centrality 3. The partnership relationship between the actors in the clinical encounter and 4. clinical empathy. Healthcare Bioethics strengthens the patient as a subject of rights and a protagonist of their healthcare, including concerning the resolution of complaints presented in this context, in contrast to the Principlist Theory, which considers the health professional as the protagonist of the moral selection of bioethical issues, not recognizing, in practice, the role of the patient as the protagonist of their care. Thus, analyzing the complaint systems in light of the new paradigm based on the Healthcare Bioethics perspective, health systems and organizations must employ complaint systems centered on patients to recognize their voice and, consequently, their needs and their family member’s needs in healthcare.

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