REVIEW

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Healthcare bioethics: a new proposal of ethics for clinical practice

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Author contributions

Aline Albuquerque and Cintia Tanure carried out the literature review and definition of intellectual content, as well as drafted the original manuscript. All authors have read and approved the final manuscript.

Competing interests

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Abbreviations

PCC, Patient-Centered Care; SDM, Shared Decision-Making.

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Abstract

The expression “patient revolution” is the social, educational, cultural, and political movement initiated at the end of the twentieth century and beginning of the twenty-first century, which sustains the protagonism of the patients in their care as the primary decision maker and holder of human rights. The patient revolution comprises varied approaches and references, such as Patient-Centered Care, Shared Decision-Making, Patient Participation, and Patients’ Rights, which combine to uphold that the patient is a moral agent and anchor healthcare in the biopsychosocial model. In this sense, this movement is a new proposal of ethics for clinical practice. This theoretical research primary goal is to develop theoretical contributions that support this new Bioethics dimension, emphasizing the context in healthcare that calls for new ethics in clinical practice, characterized as a patient revolution movement. We concluded that the patient revolution had driven a new paradigm in healthcare based on Patient-Centricity, SDM, and Patients’ Rights. Despite this critical change in the health sphere, the patient revolution appears to have reverberated in clinical bioethics. Thus, theoretical contributions must be developed for new ethics in the clinic, a task undertaken in this article through the proposal of Healthcare Bioethics as an adequate frame of reference to be adopted at all levels of clinical care. Thus, it is concluded that having Bioethics Healthcare as a beacon of ethics in clinical encounters can contribute to the quality of care and its ethical provision, confronting practices that violate Patients’ Rights. It is imperative to change paternalistic theoretical frameworks that mitigate the Patients’ Right to participate in every decision regarding their health. Only with the adoption of new approaches and an insight into the patient’s role in clinical interaction can a new culture in Patient-Centered healthcare take shape.

Keywords: patient; bioethics; healthcare; Patients’ Rights

Introduction

Clinical practices have been the subject of Bioethics since its emergence in the 1970s, notably through the studies of Hellegers, an obstetrician and gynecologist who was the founder and first director of the Kennedy Institute of Ethics at Georgetown University. The civil rights movement, especially in the United States, in which body autonomy and the issue of degrading treatment in mental health have come to light, is associated with Hellegers's initiatives. Thus, ethics in healthcare has become one of the main themes in the bioethical field, which was consolidated with the publication of the book *Principles of Biomedical Ethics*, in 1979, by Beauchamp and Childress [1], which is understood as the fundamental work of Principlism, one of the theoretical aspects of Bioethics. This Bioethics is called clinical bioethics, which sets standards for guiding clinical practice aimed at driving the work of health professionals to act appropriately when dealing with patients [2]. clinical bioethics is the "field of action capable of detecting, analyzing, understanding and trying to solve the moral conflicts that occur in the treatment or individual care of the patient" [2].

In Brazil, clinical bioethics has been inappropriately understood as a theoretical-practical framework founded on the four principles of principlism: the principle of respect to autonomy, of beneficence, of non-maleficence, and of justice [3]. Thus, principlism, despite being broadly criticized over time, is still hegemonic in the clinical sphere. It is uncritical acceptance and unreflective use in clinical issues, especially by researchers in Biolaw and Hospital Bioethics Committees, are remarkable. Consequently, it can be said that clinical bioethics in Brazil is frozen in time since it has not incorporated the so-called "patient revolution" [4, 5]. The expression "patient revolution," as used in this article, is the social, educational, cultural, and political movement initiated at the end of the twentieth century and beginning of the twenty-first century, which sustains the protagonism of the patients in their care as the primary decision maker and holder of human rights. Patient revolution comprises varied approaches and references, such as Patient-Centered Care (PCC), Shared Decision-Making (SDM), Patient Participation, and Patient Rights, which combine to uphold that the patient is a moral agent and to anchor healthcare in the biopsychosocial model. In this sense, this movement is opposed to paternalistic practices. It is connected with proposals to overcome principlism and other aspects that still confer epistemic primacy on health professionals and do not recognize that one of the most pressing ethical issues in clinical practice concerns the severe asymmetry of power between the professional and the patient. Since principlism epistemologically privileges the professional and neglects the asymmetry of power, clinical bioethics has not competed over time to face the dehumanization of the patient and practices that violate their human rights [6]. In this sense, to a large extent, the Hospital Bioethics Committees, when employing the principles of Beauchamp and Childress, consider conflicts and ethical dilemmas that are understood as such by the professional, giving them a privileged space and voice, as well as placing the same value on the human rights of patients as on the professional´s obligations, misunderstanding what Bioethics and Deontological Ethics are.

To build a bioethical theory that incorporates patient revolution and that starts from the understanding that the issue of power asymmetry is central to any ethical analysis in the clinical environment, Albuquerque [3], Jeffrey [6] and Churchill, Fanning, and Schenck [7] have been developing studies towards building a new theoretical approach of clinical bioethics, which is Healthcare Bioethics. These studies are based on a critical perspective on principlism and the necessity to construct a new approach to Healthcare Bioethics that emerges from the movement primarily structured on three approaches, the PCC, the SDM, and the patient's rights. Consequently, it is essential that these approaches be understood so that Healthcare Bioethics incorporates its ethical framework and does not make the same mistakes as principlism, such as dissociation from what is currently advocated about the role of the patient, the decision-making process, the importance of the partnership between professionals and patients, as well as the recognition that patients rights violations frequently occur in healthcare worldwide.

Thus, this article's primary goal is to develop theoretical contributions that support this new Bioethics dimension, emphasizing the context in healthcare that calls for new ethics in clinical practice, characterized as a patient revolution movement. Therefore, the scope ultimately suggests that bioethicists and Hospital Bioethics Committees consider the need to rethink Principlism based on clinical bioethics grounded on new substantive ethics capable of providing arguments, criteria, and justifications for the analysis of cases and proposing specific conduct guidelines. Considering the studies previously carried out, this theoretical article is based on the research by Albuquerque [3], Jeffrey [6], and Churchill, Fanning, and Schenck [7] regarding the proposal of a new dimension for clinical bioethics. As for the PCC and SDM, the proposed reference is anchored in the principles of the Picker Institute, dedicated to promoting the PCC worldwide through research on the subject and training health professionals to better understand the patient's perspective [8]. The reference adopted for SDM was based on the Ottawa Decision-Making Support Model, which aims to provide structured support for the decision-making of patients and families during deliberation on health decisions [9]. About Patients' Rights, its formulation was based on the investigations by Cohen e Ezer [10], Albuquerque [11], Andorno [12], Annas [13] e European Commission [14].

Patient revolution movement: Patient-Centered Care, Shared Decision-Making, and Patients´ Rights

The article by Richards et al. [5] that alludes to the patient revolution focuses on the importance of the partnership between the patient and the health team to improve health services and the need to challenge practices and behaviors deeply rooted in the clinical environment. This revolution implies changing a culture after years of paternalism and rejection of the patient's voice. In the article, there is a wide range of examples of strategies, measures, and initiatives that aim to change this culture through patient engagement and empowerment, promotion of SDM, and partnership between patients and professionals. Furthermore, the patient revolution movement was also built by another social movement, the recognition of the patient as a subject of law and a moral agent. Therefore, it is understood that Healthcare Bioethics has a context from which the patient revolution emerges, constituted by the PCC, the SDM, and the Patients' Rights. Therefore, the three approaches that include this movement will be outlined below, the PCC, the SDM, and the Patients' Rights.

Patient-Centered Care

PCC has been associated worldwide as a model related to increased quality and safety measures in clinical interactions between patients and health professionals. As opposed to paternalistic clinical practice, the PCC is a moral imperative with an invaluable purpose, regardless of the clinical results it produces [15].

PCC assumes that knowledge about physiology, diagnosis, and treatment is not enough to understand illness or manage a chronic health problem in its full complexity [16], requiring a holistic view of the patient as a unique being in their health/disease process [17].

The World Health Organization has published numerous studies considering changes in global health systems, influenced by the increase in chronic diseases due to infectious diseases, and emphasizing the need to adopt the PCC model in all levels of care and to place the patient at the center of care (WHO, 2015).

Historically, the origin of the term "Patient-Centered Care" is attributed to different authors. It was first mentioned in 1952 in a nursing journal that described a personalized patient care plan [18]. Another origin cited more frequently refers to the sketches initiated in 1957 by psychiatrist Michael Balint, accompanied by his wife Enid Balint, who carried out studies called Patient-Centered Medicine, defining it as the total experience of the patient's illness [15]. But it was not until the late 1980s that the inclusion of the patient in the center of healthcare gained strength and began to be disseminated mainly through the Picker Institute. In 1993, the Picker Institute and the Harvard School of Medicine conducted studies that identified eight dimensions/principles of PCC published in the book *Through the Patient's Eyes: Understanding and Promoting Patient-Centered Care*, defined as 1) Respect for the patient's preferences and values, 2) Emotional support, 3) Physical comfort, 4) Information, communication, and education, 5) Continuity and transition of care, 6) Coordination and integration of care, 7) Involvement of family and friends, and 8) Access to care [8].

In 2001, the US Academy of Medicine published the report "Crossing the Quality Chasm," which called for a transformation in the health system based on six primary objectives, with PCC being referenced as a central component for the quality and safety of healthcare [16]. This report is considered a benchmark for applying and disseminating PCC worldwide. After this report, many public and private health organizations, managers, and professionals in several countries have worked to implement the PCC at different levels of care.

PCC is care organized around the patient. It is a partnership model between health professionals, patients, and family members that seeks to identify and respect patients' needs and preferences [8]. To promote PCC, patients must have the guidance and support to make decisions and participate in their care [16].

The literature has no consensus on the most appropriate definition for PCC. It may vary according to the level of healthcare or the type of professional/team in clinical care. However, their point in common recognizes the need for meaningful patient involvement and engagement while in healthcare [19].

International studies have described the impacts of adopting the PCC model. They associate this model with a decrease in the number of unnecessary tests and examinations, a greater adherence of the patient to their treatment regimen, a significant increase in patient satisfaction with the conduct of their health/disease process, and a substantial increase in the patient's ability to participate in the decisions regarding their health actively [19].

Cultural changes and the formulation of a bioethical framework based on patient-centeredness are necessary to establish PCC. This implies learning to speak and listen to patients, adopting new ways of providing care, and overcoming fears or learned behaviors [20].

Shared Decision-Making

To promote PCC, the participation of patients during their healthcare has been the subject of constant discussions such that it has expanded the search for a model of care that helps in decision-making in the face of an increasing number of healthcare/treatment options.

To promote the principles of PCC that seek patient engagement, the relationship model recommended for implementation is SDM, which includes subthemes such as autonomy, empowerment, and involvement in the treatment [17]. Therefore, the patient's right to participate in decisions about their healthcare concretizes their self-determination, which is intrinsically correlated with SDM [11].

SDM is considered the core of PCC and represents a complex set of behaviors professionals and patients must achieve during healthcare [21]. Therefore, it recognizes the ethical duty of sharing important decisions with patients about their lives.

SDM emerged almost simultaneously with PCC, but its use predominated after the 1990s. The first reference to this model appeared in 1982 in the *Presidential Commission on Ethics,* which recommended SDM as an ideal model of the clinical relationship between health professionals and patients [21].

However, it was mainly because of an article by sociologist Cathy Charles that the term SDM gained worldwide attention and quickly spread to countries such as Canada and the United States in the field of interventions to increase clinical decision-making. It highlighted the main components of this process, such as the equitable involvement of the main agents – the patient and the health professional – the sharing of information by both involved, the need for a consensus between the parties on the preference of treatment and the agreement of the final option to be implemented [22].

SDM is the process by which healthcare professionals and patients make decisions together. It advocates patient involvement in any healthcare decision, including those with one or more options [23]. It recognizes the unique experience of those involved in this context, with health professionals being experts in diagnosing the problem and identifying known options, benefits, and harms, in addition to other outcomes and probabilities of outcomes that may be scientifically uncertain. On the other hand, it recognizes the patient as an expert in understanding their circumstances and in judging the value or personal importance they attribute to the known benefits or harms of each option or other scientifically uncertain outcomes that present themselves [23].

SDM is an interpersonal and interdependent process in which health professionals, patients, and their caregivers mutually relate and influence each other while collaborating on patient health decision-making [21]. For this to happen, respect and equality between the parties involved are fundamental, and a relationship of horizontality between those involved is established. SDM depends on the knowledge and understanding of the best possible scientific evidence for each health problem and the risks and benefits of all possibilities of action while ensuring that patients' values and preferences will be considered [21].

The health professional must be involved in the entire process, from the moment the decision is identified to presenting the evidence and advising the patient to implement the strategy that will bring greater comfort [21]. The underlying principle is that the professional has the technical knowledge, and the patient has the experiential knowledge.

SDM, in its most profound meaning, is the restoration of the autonomous capacity of the patient to mitigate the power asymmetry existing in the clinical encounter, mainly due to a difference in the valuation of the knowledge and experience of each of the participants [24].

The central premise of the Ottawa framework for SDM is that there is an increase in the quality of decisions that use structured aids that address each patient's specific needs. Therefore, this SDM model addresses three main fundamental elements: the first element is the approach to decision requirements that can affect the quality of the decision; the second element is the decision results that define whether the option was described in an informed manner and based on patients' values; and the last element is related to what type of structured care support is used during the deliberation of the available options [23].

It is important to emphasize that SDM is based on narratives, personal connections, intuitions, emotions, and relationships between two experts – patient and professional – in search of the best option based on scientific evidence and that consider the needs and values that are important for the patient, who should be at the center of healthcare [24].

Patients' Rights

The recognition of patients as subjects of law dates back to the 1970s. Annas [13] points out that "the idea that patients have rights was strange and even quixotic until the early seventies." At that historical moment, Patients' Rights movements gradually began to change the healthcare landscape [13]. The civil rights movement in the United States, aligned with feminism and the activism of psychiatric hospital inpatients, has called into question the idea of medical power over the patient's body and brought to light the ethical-legal obligation to respect the patients' self-determination. Similarly, in the 1960s, consumer law movements embraced health issues and challenged medical paternalism [25]. In this context, the avant-garde publication in 1970 of the book *The Patient as Person,* written by the American bioethicist Paul Ramsey [26], draws attention, placing the patient not only as a decision maker but principally as the author of their life. The seventies also saw the adoption of the first Charter of Patients' Rights, in the hospital sphere, by the American Hospital Association in 1973. This Charter was revised and replaced by the Partnership in Patient Care in 2001 [27]. In Europe, the movement for Patients' Rights has drunk from the source of human rights, not only from the point of view of individuals but also from the social activisms in which they are inserted [28]. Thus, before the 1970s, there was no demand for Patients' Rights to be legally established [29].

The Patients' Rights movements were based on two premises: a) individuals have rights that are not automatically withdrawn from them when they are admitted to a hospital or when they are in healthcare; b) most health professionals and health service providers fail to recognize these rights and protect them, and they limit their exercise. It is important to emphasize that these movements did not start from the idea that Patients' Rights would entail an opposing view of the relationship with health professionals. However, on the contrary, it was understood that the lack of care for Patients' Rights led to the dissatisfaction of patients and their families and, consequently, to an adversarial relationship. The reason is that if health professionals and the patient acted in partnership, with mutual respect and understanding, the articulation of Patients' Rights would improve this relationship [13].

Patients' rights establish moral minimums in healthcare [11] because they are derived from human rights and are anchored in the human dignity of patients, which offers a comprehensive moral structure evoked to promote the well-being and self-determination of the patient. Thus, having the patient's dignity as a guide of conduct imposes specific moral duties on the health professional, such as respecting and promoting patients' self-determination and acting following the patient's values, beliefs, and life plans. According to [12], the conception of dignity applied to the context of healthcare contributes to each patient being seen not only as someone who is sick but as a person, that is, a unique and irreplaceable human being with intrinsic value. This idea requires health professionals to consider the patient's experiential knowledge, encompassing their personal history and life experiences that make them distinct from others.

Criticism of principlism from the perspective of patient revolution

Understanding the importance of proposing new Bioethics for the clinic presupposes understanding the critical aspects of principlism and its failure as a bioethical theory to contribute to a new culture in healthcare based on patient centrality and patient-professional partnership. Principlism has not been effective in confronting the dehumanization of the patient in clinical practice and his removal from the decision-making process [6]. Principlism has been the target of criticism over the years; however, the criticism has not been based on the patient's protagonism and the need to change the culture of power asymmetry and neglect of the patient's voice. It can be claimed that there is a gap between clinical bioethics and movements in the health field that have been establishing a new moral status for the patient regarding their care.

Principlism is a reference of Bioethics composed of four principles: respect for autonomy, non-maleficence, beneficence, and justice. These principles are called by the authors themselves principles of biomedical ethics, whose scope covers healthcare and research involving human beings [30]. Principlism is a theory that is not explicitly intended for healthcare but instead seeks to establish principles and rules for various areas of health, such as research involving human beings, resource allocation, public health policies, and clinical practice. Being very broad, principlism does not consider the role of the patient and their specificities, such as their increased cognitive, emotional, and physical vulnerability [3]. Principlism does not deepen the relationship between health professionals and patients, nor the asymmetry of power inherent to it. Thus, in principlism, the patient is not the central agent of care and the primary decision-maker, leading to the assumption that Patients' Rights derive from professional obligations and not the other way around. In other words, in principlism there is an epistemic privilege of professionals because the demarcation of bioethical conflict is made from these professionals' perspective and not from the patients'. Moreover, the obligations of professionals are considered to exist per se, despite the right of the related patient. This can be exemplified based on the ethical issues pressing for patients regarding their safety and communication, which principlism does not address.

Concerning the prominence of the professional obligation when compared with the Patients' Rights, principlism does not consider that the purpose of healthcare is the patient's well-being and quality of life, according to their will and preferences, and that, therefore, falls on the patient's body, health and life. This consideration turns patients into protagonists and the central part of healthcare; the professional is relevant, but not a significant amount of it. In this sense, the obligation of the professional to do good, for example, does not exist regardless of the patient's right to self-determination; on the contrary, it arises from the right itself. In addition, Principlism has the health professional as its main interlocutor and establishes commands for their conduct, as if conflicts and ethical dilemmas were "the professionals' problems," neglecting that the patient is the primary decision-maker in healthcare [31].

Another point to be highlighted concerns the conflicts or moral dilemmas to which Principlism gives emphasis and which are excessively complex and are not those that occur in the daily life of healthcare [7]. Thus, it can be affirmed that Principlism starts from a view of Bioethics as a theoretical discipline intended to resolve conflicts and extraordinary problems, disregarding that Bioethics has a central role in constructing moral standards in daily care, which should guide the relationship between professionals and patients. As a result, Principlism does not incorporate the view that the relational dimension of care is an essential aspect of clinical outcomes, the efficiency of health systems, and decision-making, expressed in SDM, as will be addressed in this article.

In sum, we sought to expose the main criticisms of Principlism from a particular perspective: the patient centrality and the importance of the patient's relationship with the professional. Indeed, a new ethics for healthcare is needed, one that is seriously committed to patient centrality [7]. Based on the critical framework presented, the following will outline the proposal for a new Bioethics to guide clinical practices based on the PCC and the SDM and the prescriptive dimension of the theoretical-normative references of PHR (Patients' Human Rights).

Healthcare bioethics: proposition of new ethics for clinical practice

Healthcare Bioethics consists of an aspect of clinical bioethics that supports the biopsychosocial model, patient centrality, and the importance of the human connection between professional and patient. In addition, this dimension advocates a transition from the predominance of the professional's voice and biomedical evidence in the clinical encounter to taking into account the patient's experiential knowledge in a serious manner [32], as well as a transition from a clinical practice "guided by the disease or the task to be fulfilled" to one "guided by the patient" [33]. Howick and Rees [34] point out that there is a new paradigm in healthcare in which the central axis of clinical practice is the human relationship. According to this new paradigm, some fundamental elements directly interest Healthcare Bioethics: (a) empathic communication is understood as an effective intervention in itself; (b) patients' views and experiences are valued as part of the decision-making process; (c) the ability of patients and caregivers to access, understand and use health information is supported. As noted, this new paradigm is combined with the movement of the patient revolution and its two main approaches, the PCC and the SDM, which will be analyzed in this article. Considering the formulation above, a dimension of clinical bioethics is expected to promote relationships between professionals and patients that recognize the patients' individuality and address their concerns [6].

Healthcare Bioethics has as a source for the formulation of its theoretical contributions the experience of the patient, without neglecting the role of the professional since the relationship between both is one of the contributions of this structure. But, unlike other bioethical aspects, it is not the clinical experience of the professional that will dictate the substrate on which the central themes and their contributions are built. Thus, Healthcare Bioethics is based on clinical empathy and its developments in the various components of care quality, such as communication, professional-patient partnership, and patient centrality [3]. These theoretical contributions are combined with the respect and promotion of patients' human rights applied to healthcare, which must be observed *prima facie* by everyone, including health professionals. It should be noted that there is currently no ethical approach that should not consider human rights, especially when it comes to the context in which one of its agents presents a condition of increased vulnerability, such as the patient.

Thus, Healthcare Bioethics consists of theoretical contributions and normative prescriptions. These theoretical contributions are divided into three axes: (a) empathic communication between health professionals and patients; (b) partnership relationship between health professionals and patients; (c) patient centrality and empowerment, whose voice must be amplified in healthcare. Its normative requirements are established by the theoretical-normative framework of the PHR (Patients' Human Rights). The theoretical and referential axes of the PHR will not be the object of development in this article, and they will only be outlined.

Initially, concerning empathic communication, it is noteworthy that the communication between the professional and the patient is not only a technical skill to be "trained" but an ethical component of healthcare. Addressing ethical issues, such as those commonly mentioned in Bioethics books that involve patient-professional interaction, presupposes treating communication as a central element of the interactions between both. Conflicts or ethical disagreements must be faced, which implies dialogue and exchange – that is, communication. Healthcare Bioethics places empathic communication as a moral obligation of health professionals; it is not a choice but an ethical imperative.

As for the second axis, the professional-patient relationship is an ethical component of healthcare that should be the object of policies of institutions and health systems because the patient's trust in the professional is a determining factor for the positive results of their care. Notably, the expected clinical outcomes derive not only from examinations, procedures, and medical treatments but also from the quality of the connection between the care agents. In addition to the relationship being valued ethically, Healthcare Bioethics advocates that this relationship is a partnership, which leads to a critical view of health litigation and defensive medicine models.

The third axis concerns patient centrality, which requires shifting the focus of moral problems from the professional's perspective to that of the patient. This implies that it is necessary to recognize that what consists of a dilemma for the professional may not be so for the patient. Traditionally, the history of Bioethics in the clinic has dealt with difficulties based on what would be morally complex for the professional. For example, the refusal of a capable adult patient who considers the treatment futile is not a dilemma for them but rather for the professional who does not accept this refusal. The ethical vector of Healthcare Bioethics is patient centrality in their care and their consequent empowerment. Over time, clinical bioethics has constituted itself as an ethics aimed at guiding the moral dilemmas raised by health professionals to confer tools for these dilemmas to be solved. These tools are rules or moral obligations directed toward professionals based on the idea that these rules exist without the patient. It is as if the professional had the duty of confidentiality regarding the patient's personal data disconnected from what justifies it, which is the protection of the patient's privacy. Distinctly, Healthcare Bioethics, taking into account patient centrality, provides an ethical tool for solving moral issues regarding the rights of patients and its three theoretical-practical axes.

The guiding component of Healthcare Bioethics was developed in other research [3, 11]. In any case, although not the focus of this article, it should be noted that by incorporating the language of rights into its scope, Healthcare Bioethics is considered a "right-friendly theory" [35] since the language of Patients' Rights is the essential normative tool of Healthcare Bioethics.

Conclusion

The patient revolution has driven a new paradigm in healthcare based on patient-centricity, SDM, and Patients' Rights. Despite this critical change in the health sphere, the patient revolution appears to have reverberated in clinical bioethics. Thus, theoretical contributions must be developed for new ethics in the clinic, a task undertaken in this article through the proposal of Healthcare Bioethics as an adequate frame of reference to be adopted at all levels of clinical care. Thus, it is concluded that having Bioethics Healthcare as a beacon of ethics in clinical encounters can contribute to the quality of care and its ethical provision, confronting practices that violate Patients' Rights. It is imperative to change paternalistic theoretical frameworks that mitigate the patient's right to participate in every decision regarding their health. Only with the adoption of new approaches and an insight into the patient's role in clinical interaction can a new culture in patient-centered healthcare take shape.

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