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

Rev. Bioét. vol.33 Brasília 2025

# Bioethics in primary health care: moral experience, territory, care

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## Abstract

In recent decades, several reflections and research on bioethics in primary health care have been carried out, but a proposal has not yet been established. In general, these proposals argue that bioethics in primary health care should consider particularities, problems and contexts of primary health care, which are different from health care in hospital institutions. However, there is no progress on this issue and attempts are still being made to apply clinical bioethics with a "hospital" logic. This article aims to reflect on some possible reasons for the low impact of bioethics in primary health care and to present a general proposal for bioethics in primary health care based on moral experience, territory and care. This is the first step towards the development of a more complete proposal for bioethics in primary health care.

**Keywords:** Bioethics. Primary health care. Sociocultural territory.

## Resumo

**Bioética na atenção primária à saúde: experiência moral, território, cuidado**

Nas últimas décadas foram realizadas diversas reflexões e pesquisas sobre bioética na atenção primária à saúde, mas ainda não foi estabelecida uma proposta. De modo geral, essas propostas defendem que a bioética na atenção primária à saúde deve considerar particularidades, problemas e contextos da atenção primária à saúde, que são diferentes da atenção à saúde nas instituições hospitalares. No entanto, não há progresso nessa questão e ainda são realizadas tentativas de aplicar uma bioética clínica com uma lógica "hospitalar". Este artigo tem como objetivo refletir sobre algumas possíveis razões para o baixo impacto da bioética na atenção primária à saúde e apresentar uma proposta geral para a bioética na atenção primária à saúde baseada na experiência moral, no território e no cuidado. Esse é o primeiro passo para o desenvolvimento de uma proposta mais completa de bioética na atenção primária à saúde.

**Palavras-chave:** Bioética. Atenção primária à saúde. Território sociocultural.

## Resumen

**Bioética en atención primaria de salud: experiencia moral, territorio, cuidado**

En las últimas décadas se han presentado diversas reflexiones e investigaciones sobre bioética en atención primaria de salud, sin embargo, ninguna propuesta ha logrado establecerse aún. Generalmente estas propuestas señalan que la bioética en atención primaria de salud debería considerar las particularidades, problemas y contextos propios de la atención primaria de salud, que son diferentes de la atención de salud en instituciones hospitalarias. No obstante, no se ha logrado avanzar en esa dirección y se sigue intentando aplicar una bioética clínica de lógica "hospitalaria". Este artículo pretende reflexionar sobre algunas posibles razones del bajo impacto que ha tenido la bioética en atención primaria de salud, y presentar una propuesta general de bioética en atención primaria de salud basada en la experiencia moral, el territorio y el cuidado. Esto representa el primer paso hacia el desarrollo de una propuesta más acabada de bioética en atención primaria de salud.

**Palabras clave:** Bioética. Atención primaria de salud. Territorio sociocultural.

The author declares no conflicts of interest.

Bioethics in primary health care (PHC) has been taking its place in recent decades [1,2]. In Chile there are even publications dedicated to the subject [3]. In general, the texts highlight that, given the different characteristics of primary care in relation to hospital care, bioethics in PHC must also be diverse and correspond to the particularities, problems, and contexts of PHC. However, this diverse analysis was not elaborated with the intensity, breadth and rigor of clinical bioethics. For González-de Paz, *the uniqueness of the structure of care with PHC has been mentioned on several occasions, however, the differentiated analysis of clinical bioethics has not been widely explored* [4].

In this sense, most bioethics training programs in higher education focus on the most general and socially debated ethical issues or the most "spectacular" and cutting-edge technological themes, providing tools to deal with these issues, for example, for decision-making in cases of critically ill patients at the beginning or end of life, but it does not take into account the ethical problems of PHC [5-8]. Without hesitation, we can affirm that clinical bioethics has been mainly hospital-based [9].

With this in mind, considering that it has been a long time since the Declaration of Alma-Ata and that bioethics has been formally discussed in PHC, we elaborate on this question: Why have the contents of this discipline not yet been implemented? Why was its impact not significant? [10] We still do not have answers to these questions, but we can provide reflections that can shed light on them.

## Criticisms of bioethics in primary health care

First, although the texts on bioethics in PHC seek to point out the need for a specific bioethics [11], when they delve deeper into this issue, they cannot get out of the generalist perspective of the four principles of bioethics, which, as we know, are the primordial framework of clinical bioethics. And although they use different principles from the four classics, the logic of the principles has not changed. Basically, the need to develop a specific bioethics was not fulfilled.

Secondly, many bioethics articles in general have little theoretical rigor in their analyses, carrying out a mixture of theories, points of view, approaches, "paradigms," etc.; and, on many occasions, the terms "values," "principles," "norms," "duties," "virtues" are treated as synonyms. A clear example is the approach to bioethics in one of the most important manuals of the Chilean Ministry of Health for PHC teams, the so-called *Guidelines for the implementation of the family and community comprehensive health care model* [12].

This manual defines the Chilean health system as a system based on primary care in which, based on the model of comprehensive health care, the principles that guide the work of health teams in the care network for the harm prevention to treatment are established, in a way that is increasingly inclusive of other health needs within the family and community. The manual seeks to update the fundamentals and scope of the comprehensive health care model, emphasizing how to put its principles into practice.

Point 4 of chapter I of this manual presents the ethical aspects in the work of health teams according to the updated PHC. In this section, values, principles, and essential elements in a health system based on PHC are exposed, and then link each of these essential elements to different ethical principles and frameworks, supposedly according to each element. These ethical principles and frameworks are basically what healthcare teams should know in order to do a proper job in developing the elements. And there is a real collage.

In a few paragraphs and very superficially, several theories of the Western ethical tradition are raised (Kantian ethics, utilitarian ethics, ethics for technological civilization, ethics of care), almost only naming them, together with the principles of bioethics, some rules, etc., trying to link them to each of the elements, as can be seen in Chart 1 as presented in the text of the Ministry of Health.

**Table 1.** Elements of updated PHC in relation to the associated ethical principle or framework that it proposes to integrate [12]

| Updated PHC Element | Ethical principle/Framework |
|---|---|
| **Universal access and coverage** | Justice, equity in access to health services |
| **Comprehensive and integrated care** | Ethics of care |
| **Emphasis on health promotion and prevention** | Beneficence<br>Nonmaleficence |
| **Adequate attention** | Beneficence |
| **Family and community guidance** | Ethics of care |
| **Active participation mechanisms** | Kantian ethics |
| **Policies and programs that foster equity** | Theories of justice<br>Fair opportunity rule |
| **First contact** | Respect for autonomy<br>Protection of people with disabilities |
| **Legal and institutional structure** | Community life |
| **Optimal organization and management** | Material principles of distributive justice |
| **Human resources** | Statement of local principles Care Ethics Committee (CEA) and Research Ethics Committee (REC) |
| **Adequate and sustainable resources** | Ethics for technological civilization |
| **Intersectoral actions** | Principle of responsibility |
| **Emergencies and disasters** | Practical ethics<br>Utilitarian ethics |

*PHC: primary health care*



As we can see, the "ethical principles or frameworks" related to each element correspond to different traditions or currents, for example, the "Kantian ethics" and the "ethics of care." Without order and context, the six pages about the ethical aspects of the work of health teams present ethical notions that teams must know to apply in their work, but it ends up functioning as a kind of checklist.

If the manual that aims to guide the practical work of health teams presents bioethics so informally, without depth or context, and more importantly with so little theoretical rigor, with such inadequate content, we cannot expect this text to become something significant or, at least, to be at least a kind of guide, having some impact on primary care and people's care. With this type of analysis, it will not be possible to move forward, and a true bioethics program in PHC is needed, which is significant and capable of guiding health professionals, which the manual clearly does not do.

Third, bioethics has long been transformed into an academic discipline [13] that cannot leave the walls of universities, research centers, health institutions, a question of bioethics, of some health and research professionals interested in it, a question of specialists. As Miguel Kottow has been pointing out for more than a decade: *bioethics deliberates in a vacuum due to lack of anchorage in social structures, where its reflection could be transformed into action; it risks becoming a useless passion* [14].

Little remains of the original impulse that led Pellegrino [15] to consider it a movement and not a discipline. In this sense, bioethics has mainly a unidirectional character, with communities, civil society, and their organizations as passive recipients, except in the case of activist groups. Although they do not usually expressly point it out, these groups conduct eminently bioethical work challenging institutionality or social sanctions, going deeper and advancing rapidly,

at the speed imposed by contingent problems, but they do not get lost in contingencies or in endless metaphysical discussions.

In short, they do bioethical-social-political work. We are referring to groups that fight for rights, for example, the Latin American feminist movement, that fight for women's sexual and reproductive rights, such as abortion. With the exception of cases of bioethical and political activism originating from civil society and for the care of civil society itself, bioethics as a discipline has remained more interested in its own practice, closed in on itself, with little link with society.

After several decades of existence, it is totally necessary for bioethics to be what it should be, to fulfill its social function and that, as Gracia says, it contributes *for education with autonomy, responsibility, and deliberation of all subjects*, *making them go from heteronomous to autonomous*, *from subjects to citizens*, *from submissive and obedient people to critical and mature subjects* [16], subjects capable of a reasonable and prudent management of their body, their sexuality, their life, and death.

## A bioethics based on moral experience

In a text from the early 1990s, Gracia [17], as a good connoisseur of the history of bioethics, thanks in part to his studies in the United States, clearly points out that bioethics is a typically American creation. This "typically" is no wonder, it is related to the fact that it was presided over by three factors: casuistry, proceduralism, and decisionism.

This enables us to raise, among other issues, that substantive ethics was not very present in this history, which is relevant to our study, because it mainly gave bioethics an operational and functional meaning, and may lead to it being seen simply as an application of ethics in the field of health and biomedical studies. This understanding of bioethics has imposed a kind of engineering model of moral reasoning and has become a true technology for managing problems [18]. The *application* of the principles has been central and has contributed for bioethics to assume a technical rationality, leaving its nature primarily ethical [19]. It is necessary to move from the logic of applying principles to a bioethics based on reality, on moral experience.

Conceptually, "principle" is understood as a fundamental and irrefutable statement, which serves as the basis for a reasoning, which has unchallenged validity and is not subordinated to another [20]. In traditional ethics there were attempts to establish principles, the most classic being Kant's categorical imperative, which was immediately criticized for its detachment from the world of life, its circumstances, and concrete situations.

In bioethics, principles operate, in fact, as normative generalizations intended to guide actions. Beauchamp and Childress point out that *Principles do not function as precise rules of behavior that establish how to act in each circumstance* (...) *These are general guidelines that leave considerable room for judgment in specific cases* [21]. That is why, in their application, the principles of bioethics have become simply a scheme, a grid *a priori* whose objective is to encompass the complexities of reality, which fulfill a taxonomic function without any real depth in the understanding of moral experience.

Principles are derived from a previous phenomenon, values. This is rarely mentioned, but the principles are created from the projections we make; the main phenomenon is evaluation. For example, if there is the principle of non-maleficence, it is because we previously valued people's lives and integrity and, therefore, considered that we should not harm them. Values, as primary phenomena, are directly linked to reality, which is why we think bioethics should focus on values and not principles, on the construction of values, since it is from this that the duties (principles) that we consider ethically correct derive.

The interesting thing about this is that, as values are projections of reality, they are a situated phenomenon, with a context and a collective construction. A bioethics based on values, rather than principles, does justice to people's experiences and enables us to try to better understand each individual's decisions [22].

It is time to go beyond bioethics as an application scheme if we really want a bioethics with ethical and not legal foundations [23,24]. This means that bioethics

in PHC needs to be closer to reality, to the moral experience of subjects and groups, to their contexts and circumstances, to their projections, reflections, and decisions, understanding that what is at stake is their care and life, and not the self-affirmation of the bioethical discipline.

## Bioethics from territory

The transition from bioethics under the logic of the application of a scheme of principles to a bioethics that emerged in the space where people's lives, conditions, and circumstances are developed and reproduced leads us to consider another issue in this proposal: territory.

The concept of territory, which emerged in geographical thinking, has been used by several disciplines, especially in the social sciences such as sociology, anthropology, economics, etc. It has become an interdisciplinary concept, for *being part of the theoretical references of various disciplines that have as their object of study the multiple types of relationships presented by human beings* [25]. In health sciences, this also occurs and helps the understanding of the health-disease-care process from a new dimension [26], which in our case is fundamental, since the bioethical issues and problems of PHC occur there.

The first approaches since the public hygiene movements of the eighteenth century considered the territory as an external space, an entity independent and separable from social activity. As Molina points out, *the territory is conceived as a space that contains natural hazards and a politically delimited area under the administration of the State; it is a variable of geographical-environmental delimitation, which is supposed to be independent of social processes of a broader political and economic order* [27].

Since the social medicine of the eighteenth century and throughout the twentieth century, the economic, political, and cultural factors of the configuration of territories have been added to environmental factors to try to explain the emergence of diseases. *Territory is understood in this case as a spatialization of the power of the State, as a political-administrative entity and physical scenario, in which the social determinants of the disease are located* [27]. Territorial units are organized and managed "from above" by State power, and in this sense territory is still understood as a mode of organization that is external to individuals, who are territorialized by the fact that they are located in a certain space.

Linked to this way of understanding territory, the proposal of the social determinants of health is still insufficient to encompass the health-disease-care process and, in addition, *it makes the general and intermediate determinants of health invisible (globalization, class inequalities, gender determinations, among others). In this sense, it is necessary to think about the relationship between health and society beyond the "social determinants" proposed by the World Health Organization, given both the uncriticality, non-specificity and diffusivity that the "social environment"* acquires *in this perspective as to the individualizing biomedical trait that regulates its incorporation* [28].

Based on the tradition of contemporary social medicine and collective health, the territory is conceived as a social product, arising from the dynamics of the modes of production and social reproduction. *In this scenario, the analysis of health is not limited to the spatial distribution of the physical characteristics of the environment that affect the epidemiological profile of a given population; both territory and health are at the same time processes and products of social relations and modes of production, which propose specific ways of relationship with nature, of living, and of becoming ill* [27].

Territory is no longer understood with political-administrative criteria, on the contrary, it is the space of human interrelations and exchange of social daily life, in which various power relations operate, a space with a historical, political and economic, symbolic, and identity character, in which the collectives leave their traces. As Junges and Barbiani point out, *the territory is a social, real, and objective space, crossed by cultural values and meanings of subjectivity, without defined limits, since it is characterized by its symbolic dimension, not identified with territorial administrative criteria* [29].

The health-disease-care process occurs in the territory, as well as the way to understand and value this process and the aid , support, and resources networks to deal with social and health problems. In this sense, as Samaja points out [30], the object of the disciplines that we normally consider in the "health area" are the problems, representations and strategies of action that unfold in the course of the reproduction of social life.

Bioethics in PHC should deepen the territorialization process to try to encompass the territory, the health-disease-care process and the construction of values that occur there, perhaps in this way we can meet the specific bioethical needs of the group, and not apply external principles.

Entering into this process of territorialization is absolutely necessary to promote collective ways of living well and to face the discomforts that neoliberalism encourages to create individually, to collaborate with the practice of its own ways of exercising rights; at the same time, this makes it possible to reveal the determinations and conditions of the possibility of autonomy, and does not take it for granted as "traditional" bioethics does.

## Bioethics of care

There is a vast publication on the ethics of care in bioethics [31-33], but little progress has been made in deepening this relationship. In general, it is pointed out that the ethics of care has its origin in the studies of Carol Gilligan [34] on the development of moral judgment, in which another voice would be established on how to base it.

Often, such presentations are diluted in the discussion between the ethics of justice and the ethics of care and, as with many questions in bioethics, they become a repeated speech, without any original reflection, questioning, or criticism by those who make it. However, we will not go into this discussion in this article, let us get straight to the point.

Based on Tronto and Fisher, we understand care as an *activity that includes everything we do to maintain, continue, and repair our "world" so that we can live in it to the best of our ability. This world includes our body, self, and environment, everything we try to weave into a complex, life-sustaining web* [35].

This beautiful definition is fundamental to our PHC bioethics proposal. We believe that this type of bioethics, in addition to trying to understand people's moral experience and the territory in which it is situated, should be established as a node in this life-sustaining network. But not just life, but of the best possible life (which is what bioethics points out, unlike biopolitics).

Part of our proposal is a bioethics in PHC based on care: to strengthen this support network that enables collective ways of living well and coping with discomfort, a network of interdependent bonds that supports the exercise of rights, understood as minimum, and then enables us to design creative and autonomous ways of living.

As Brugère points out: *insisting on the broad interdependence of lives implies promoting another conception of coexistence, via the primacy of a democratic bond concerned with not excluding those who are confronted with situations of vulnerability, who need the attention of others, of public policies of solidarity to consider a return to the capacity for action* [36].

When we talk about autonomy throughout the text, we refer to the moral autonomy that emerged in this matrix. From the authors who cultivate the ethics of care and feminism, the proposal of a relational moral autonomy emerges, contrary to the moral autonomy that bioethics normally exercises, understood as individualistic independence.

The main criticisms of this way of understanding and treating autonomy are related to, on the one hand, thinking of it as a starting point in decision-making processes, and not as a point of arrival and aim of the process. In other words, respect for the patient is not in not interfering in the decision-making process, but in promoting the exercise of their autonomy, providing all the necessary resources for this, without abandoning them, but without being paternalistic [37]. The other criticism is more fundamental and is related to the lack of reference to the social component of autonomy, to the bonds that are constituting and conditioning the autonomy of an individual in his or her territory, and to the social repercussions of decisions.

In this sense, Donchin proposes to understand autonomy in a strongly relational sense *that recognizes a social component integrated into the very meaning of autonomy. That is, subject-centered activities of reflection, planning, choice, and decision-making, which enter into self-determination, are social activities in two senses: subjectively, the material for reflection is constructed on the basis of socially shared past and future expectations involving the participation of others; objectively, the options available for decision-making are shaped and limited by norms, practices, social structures, and institutions* [38].

Understood in this way, moral autonomy is constituted and conditioned in the territory, and then, in its exercise, the decisions have an impact on that territory, that is, it is relational in its origin and consequences.

## Final considerations

We believe that a bioethics in PHC must be based on three pillars to respond adequately to the demands of its context: it must be a bioethics that arises in moral experience, not in the application of principles; that investigates and tries to encompass the territorialization process; and that is part of the search to promote care practices that strengthen the aid network for collective good living and the exercise of rights and relational autonomy.

Evidently, we still have the task of deepening this proposal and making it more practical to be adequately integrated by PHC professionals and clearer in the participatory and deliberative exercise of groups in their health-disease-care process.



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**Responsible editor** – Dilza Teresinha Ambrós Ribeiro

**Received:** 7.10.2024
**Revised:** 1.24.2025
**Approved:** 1.27.2025