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Public policies and the right to health: between discourse and practice in the care of people with Cancer

Public Policies and the Right to Health: Between Discourse and Practice in the Care of People with Cancer

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SUMMARY

This article analyzes the interface between the Right to Health and humanization practices in the care of people with cancer, taking as its analytical axis the Statute of the Person with Cancer (Law No. (Law 14.238/2021). The research, qualitative in nature and with an exploratory and analytical approach, is based on the speeches and experiences shared during a dialogue session held at the Santa Teresa Faculty in Manaus, which brought together health and legal professionals, as well as the participation of a patient-activist. According to Gil (2019), exploratory research allows for the development and clarification of concepts, offering an overview of a given phenomenon, while analysis makes it possible to interpret data in light of theoretical frameworks. Thus, procedures such as bibliographic research, documentary analysis of public policies and legal norms, as well as systematized records in an observation notebook, were used. The analysis followed a hermeneutic-critical approach, according to Habermas (1987), which understands Law as a language and communicative practice, interpreting the social meanings that sustain it. The field of observation included primary care policies and disease prevention programs in the city of Manaus, focusing on oncology and women's health, in addition to the experiences reported by legal and public health professionals. It was found that legal discourse, when articulated with medical knowledge and the experience of patients, reveals tensions between the normative text and institutional reality, highlighting the need for a more humanized and dialogical state action. It is concluded that comprehensive care, prevention, and psychological support are inseparable dimensions of the right to life and the realization of human dignity.

Keywords: Right to Health; Public Policies; Humanization; Statute of Persons with Cancer.

ABSTRACT

The article analyzes the interface between the Right to Health and the practices of humanization in the care of people with cancer, taking its analytical axis the Statute of the Person with Cancer (Law No. 14.238/2021). The research, qualitative in nature and exploratory and analytical in approach, is based on the speeches and experiences shared during a dialogue circle held at Santa Teresa College in Manaus, which brought together health professionals, legal experts, and the participation of a patient-activist. According to Gil (2019), exploratory research aims to develop and clarify concepts, offering an overall view of a given phenomenon, while analysis allows data interpretation in the light of theoretical frameworks. Thus, procedures such as bibliographic review, documentary analysis of public policies and legal norms, and systematic field notes were employed. The analysis followed a hermeneutic-critical approach, as proposed by Habermas (1987), who understands Law as language and communicative practice, interpreting the social meanings that sustain it. The field of observation included basic healthcare policies and disease prevention programs in the city of Manaus, focusing on oncology and women's health, as well as experiences reported by professionals from the fields of Law and public health. The study found that legal discourse, when articulated with medical

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knowledge and patient experience, reveals tensions between normative texts and institutional reality, highlighting the need for a more humanized and dialogical state action. It concludes that comprehensive care, prevention, and psychological support are inseparable dimensions of the right to life and the realization of human dignity.

Keywords: Right to Health; Public Policies; Humanization; Statute of the Person with Cancer.

INTRODUCTION

The Statute of Persons with Cancer (Law No. 14,238, of November 19, 2021) represents a legal milestone in consolidating the fundamental rights of people diagnosed with cancer in Brazil. This legislation reaffirms the State's commitment to universal, equitable and... comprehensive healthcare, in accordance with Article 196 of the 1988 Federal Constitution, which establishes that "health is a right of all and a duty of the State." This principle underpins the functioning of the Unified Health System (SUS), supported by the pillars of universality, comprehensiveness, and equity. and broadens the notion of care beyond the physical treatment of illness, incorporating dimensions emotional, social and psychological.

In the context of Manaus-AM, however, structural weaknesses persist that They compromise the effectiveness of these rights. Primary care is still limited in scope and Effectiveness, and the referral and counter-referral flows do not guarantee continuity of care. This makes early diagnosis and timely treatment of oncological diseases difficult. This reality This reveals a disconnect between legal norms and institutional practice, especially in policies. prevention and monitoring of women's health.

The lecture series analyzed in this study highlighted this gap: the professionals' speeches. The activist-patient pointed out the disconnect between the public health service and the needs of the people. concrete issues affecting the population pose a challenge to the comprehensiveness of the SUS (Brazilian Unified Health System). The absence of policies Active public prevention efforts and a humanized support network undermine the principle. constitutional principle of human dignity and the very credibility of the State as a guarantor. of fundamental rights.

This article therefore falls within the field of Law and Public Policy, proposing a critical reflection on the state's role in the formulation and implementation of programs of prevention, diagnosis and treatment of oncological diseases, especially those affecting the The most vulnerable populations. The aim is to build a political and structural perspective on public health. advocating for the integration of health and education as a strategy for social awareness and Strengthening health citizenship.

Based on this scenario, the article analyzes the interface between the Right to Health and the practices of Humanization in the care of people with cancer, taking as its central theme the Statute of Persons with Cancer.

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Cancer. The study adopts a qualitative methodology, of an exploratory and analytical nature, supporting- whether in the speeches and experiences shared during the dialogue session with health professionals, of Law and with the participation of a patient-activist. By articulating legal discourse, medical knowledge and human experience, the article aims to contribute to the debate on the limits and possibilities on the realization of the right to health: between legal discourse and the practical reality of public policies in Manaus.

2. Theoretical Framework

2.1 The right to prevention and comprehensive care: analyzing what the law says and what reality shows.

The consolidation of fundamental rights for people with cancer had a milestone starting from... from the enactment of the Statute of Persons with Cancer (Law No. 14.238/2021), consolidating and guaranteeing the fundamental rights of people affected by the disease in Brazil. The Statute reaffirms the constitutional principles of human dignity and the right to health, as provided for in article Article 196 of the Federal Constitution, and consolidates the State's obligation to guarantee concrete conditions for its effectiveness.

However, authors such as Bobbio (1992) and Boaventura (2010) show that there is a The difference between the formal recognition of a right and its realization in everyday life. In this case In public health, this gap manifests itself in unequal access and lack of infrastructure. basic care and the slowness of diagnostic and treatment flows, especially in the regions more peripheral areas, such as the Amazon. In Manaus, for example, the fragility of the healthcare network. The primary issue reflects the difficulty in materializing what the Statute defines as "comprehensive care" and "Early diagnosis," as provided for in Articles 2 and 4 of Law No. 14.238/2021, according to:

Article 2. The essential principles of this Statute are:

- I - Respect for the dignity of the human person, equality, non-discrimination and individual autonomy;
- II - Universal and equitable access to appropriate treatment;
- III - Early diagnosis;
- IV - Encouraging prevention;
- V - Clear and reliable information about the disease and its treatment.

Article 4. The following are fundamental rights of a person with cancer:

- I - Obtaining an early diagnosis;
- II - Access to universal, equitable, adequate and least harmful treatment;
- III - Access to transparent and objective information regarding the disease and its treatment;

Authors such as Donnangelo (1976) and Paim (2011) emphasize that the right to health must be understood within a socio-historical context, in which economic, cultural and determinants Geographic factors directly influence access to care. In this sense, the Statute proposes a model which goes beyond the clinical focus on the disease and incorporates emotional, social and psychological dimensions. (art. 12, §1º), reinforcing the notion of comprehensive care:

Article 12. Comprehensive healthcare for individuals with cancer is mandatory through... of the SUS, in the form of regulations.

§ 1 For the purposes of this Law, comprehensive care is understood to mean care provided in various areas. levels of complexity and hierarchy, as well as in the various medical specialties, according to The health needs of a person with cancer, including medical and pharmaceutical care. psychological assistance, specialized care and, whenever possible, treatment and hospitalization. households.

However, the discourse of humanization and comprehensiveness still encounters practical barriers. Merhy (2002) observes that public health management tends to adopt a technocratic rationality, which fragments care and reduces the individual to an object of medical intervention. This criticism is reinforced by Ayres (2009), in defending the idea of "sensitive listening" and communicative practices that Recognize the patient as the protagonist of their own healing process.

From a legal standpoint, Mello (2005) emphasizes that the principle of legality Administrative law imposes on the State the duty to implement policies that ensure the full exercise of rights. of the rights recognized by law. Thus, the absence of structured prevention policies and Rapid diagnosis, especially in oncology, may constitute a breach of the duty to provide care. State and civil liability of public authorities.

Furthermore, the Habermasian hermeneutics used in this study contributes to understanding Law as a language and communicative practice, as proposed by Habermas (1987). From this In this approach, the Statute of Persons with Cancer should be interpreted not only as a text. normative, but as a social discourse of recognition, in which the dialogue between the State, Civil society and patients become a central element of justice and democratic legitimacy.

Thus, a critical analysis of the Statute shows that the effectiveness of the right to health depends on a systemic integration between public policies, professional training, and participation. Citizen. Strengthening primary care, expanding prevention campaigns, encouraging Interdisciplinary training and the consolidation of social and legal support networks are measures indispensable for transforming normative discourse into emancipatory practice.

In summary, the discussion reveals that the Right to Health, especially in the field of oncology, It only achieves its full potential when accompanied by an active, transparent, and humanized public policy, capable of balancing the legal, ethical, and existential dimensions of care. Thus, the Statute of the Person Cancer should be understood as an instrument of social justice and reconstruction of the pact. A civilization centered around life, dignity, and hope.

3. MATERIALS AND METHODS

The research will be qualitative in nature, with an exploratory and analytical approach. According to Gil (2019), "The main purpose of exploratory research is to develop, clarify and to modify concepts and ideas, providing an overview of a particular phenomenon. while the analysis aims to interpret the data in light of theoretical frameworks (p.27)".

The methodological procedures used are: bibliographic survey, analysis Documentary material on public policies and legal norms, and a notebook of observations. Analysis techniques. The methods used were based on a hermeneutic-critical approach to legal and theoretical sources, seeking to understand how legal discourse materializes (or does not materialize) in institutional practices, according to Habermas (1987) proposes that understanding law requires interpreting language and... Structures of meaning that underpin social and communicative action.

Field of observation: primary care policies and disease prevention programs in city of Manaus, with an emphasis on oncology and women's health cases. In addition to the experiences of Legal and public health professionals were presented at the dialogue session.

4. RESULTS AND DISCUSSION

The analysis of the data collected during the dialogue session held in Manaus revealed... a set of converging perceptions about the weaknesses of the public health system, especially with regard to basic care for cases still under analysis. The statements of Health professionals, legal professionals, and the patient-activist revealed a disconnect between the text. normative framework and institutional reality confirm that the right to health, although broadly defined, is a fundamental right.

Recognized in the 1988 Federal Constitution, it still faces structural obstacles and operational to be realized.

In general, participants pointed out that the Unified Health System (SUS), supported Despite the principles of universality, comprehensiveness, and equity, it still has some weaknesses in Continuous monitoring of cancer patients. In many cases, early diagnosis, guaranteed by article 4, item I, of the Statute of Persons with Cancer (Law No. 14.238/2021), is delayed. due to a lack of equipment, professional training, and integration between levels of care. This finding coincides with what Donnangelo (1976) already stated when defining health as a a social phenomenon conditioned by inequalities of access and by the power relations that structure it. The Brazilian state.

Furthermore, the analysis of the statements revealed a consensus regarding the importance of prevention and... Health education as a pillar of public oncology policies. However, it was observed that... Educational actions and preventive campaigns are sporadic, uncoordinated, and insufficient to achieve the desired results. vulnerable populations. Paim (2011) reinforces that the realization of the right to health depends on policies. integrated public initiatives capable of promoting and preventing disease in a continuous manner and territorialized, and not merely as episodic actions.

The hermeneutical analysis of the speeches also showed that the actions of public bodies and of Health institutions, although supported by a solid regulatory framework, lack dialogue. intersectoral and communication strategies that integrate the State, civil society, and patients. From this perspective, Habermas (1987) argues that law should be understood as practice. communicative, where consensus and mutual recognition are essential for the legitimacy of standards. Applied to the context of health, this understanding implies building policies based on Listening and social participation, not just technical guidelines.

In the legal field, the discussion about state responsibility also emerged in a way... Relevant. The delay in diagnosis and the absence of adequate follow-up constitute, according to Mello (2005), violation of the state's duty to provide services and affront to the principle of legality administrative, which imposes on the public authorities the obligation to fully comply with the rules of social protection. This perspective aligns with Bobbio's (1992) critique, which differentiates the Formal recognition of rights and their concrete effectiveness: the contemporary challenge is no longer... To declare rights, but also to ensure the means to make them enforceable.

In a convergent manner, the analysis of the experiences presented in the dialogue session pointed out that the Statute of Persons with Cancer, despite representing a normative advance, has not yet achieved The level of implementation needed to transform the reality for patients. The lack of Hospital infrastructure, delays in scheduling exams, and lack of psychological support.

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The systematized measures contradict Article 12 of the aforementioned law, which mandates comprehensive care and multidisciplinary, including pain management and palliative care.

These results reinforce the importance of understanding law not only as a norm, but as an instrument for social transformation and the humanization of public policies. As observed Santos (2010) argues that it is necessary to "radicalize democracy" so that the law is not merely proclaimed. But it is lived experience, and this requires communicative practices, intersectoral policies, and ethical engagement from everyone. public officials.

Therefore, the findings of this study indicate that the effectiveness of the right to health depends on Integrated actions between public management, social control, and citizen participation. Implementation The Statute for People with Cancer needs to be accompanied by investments in infrastructure. training of professionals, ongoing educational campaigns and monitoring mechanisms democratic. Only in this way can legal discourse be transformed into concrete practice, guaranteeing to People with cancer deserve not only medical treatment, but also the full exercise of their right to life and to... dignity and hope.

5. CONCLUSION

The analysis presented in this article showed that the right to health of a person with cancer, although solidly supported by the Federal Constitution of 1988 and the Statute of Persons with Disabilities Cancer (Law No. 14.238/2021) still faces a chasm between normative discourse and the reality of... Brazilian public policies. The study showed that, in contexts such as that of Manaus-AM, the Weaknesses in primary care, lack of integration between levels of the SUS (Brazilian Unified Health System), and scarcity of actions. Systematic educational practices compromise the realization of this right, especially among populations. vulnerable.

It was found that early diagnosis, one of the principles expressly provided for in The statute still represents a goal far from being achieved in practice. The gap between the legal text... and its execution reflects not only administrative shortcomings, but also a bureaucratic culture. which often reduces the patient to a number, neglecting the emotional and social dimensions. and psychological aspects of care. This finding reinforces the interpretations of Merhy (2002) and Ayres (2009), according to which healthcare should be understood as a human interaction and communicative, in which listening and bonding become an essential part of the therapeutic process.

By adopting a hermeneutic-critical approach inspired by Habermas (1987), It is understood that the Right to Health only achieves legitimacy when it is constructed in dialogue with the society. The effectiveness of the law depends on the State's ability to transform legal language.



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in participatory, transparent, and intersectoral practices. In this way, the strengthening of policies Public policies require dialogue between health, education, and justice, as well as permanent spaces for listening. and social control, such as councils and public conferences.

The Statute of Persons with Cancer, in recognizing comprehensive care and support Psychosocial recognition as an inalienable dimension of human dignity represents a legal advancement and ethical. However, its full implementation requires more than regulation: it requires political will, planning, and social commitment. It is essential that public managers, health professionals, and Legal professionals should act collaboratively, guided not only by the law, but also by... principles of solidarity and distributive justice.

The right to health, especially in the fight against cancer, is a field that demands... Continuous vigilance and reflection. Research confirms that legislation alone is not enough; it is necessary to put it into practice. rights through actions that restore to the citizen the leading role in their own life. Care Comprehensive care, prevention, and psychological support are not favors from the State, but expressions of its own actions. concrete aspects of human dignity.

Therefore, this study reinforces that the future of public health policies in Brazil depends the ability to align discourse and practice, transforming the letter of the law into action, the norm into Presence and the Law in Life.

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