Vulnerability, Care, and integrality: conceptual reconstructions and current challenges for HIV/AIDS care policies and practices

Vulnerabilidade, Cuidado e integralidade: reconstruções conceituais e desafios atuais para as políticas e práticas de cuidado em HIV/Aids

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ABSTRACT Health practices in general, and the response to the HIV/AIDS epidemic in particular, are going through a critical and challenging period in Brazil's current social and political context. This essay aimed to discuss some of these challenges and the conceptual constructs that are considered relevant as resources for facing them. The reflection highlights resistance to biomedicalization, to individualizing approaches and to the abandonment of the perspective of human rights as major challenges in the fight against AIDS, and discusses how the reconstructive concepts of vulnerability, care, and integrality, developed in the context of the health reform, the conformation of the Unified Health System (SUS), and the very construction of the Brazilian response to the HIV/AIDS epidemic can bring relevant subsidies to resist the dismantling of the achievements conquered and the construction of new emancipating paths for collective health.

KEYWORDS Acquired Immunodeficiency Syndrome. Human rights. Health vulnerability. Integrality in health.

RESUMO *As práticas de saúde de modo geral, e a resposta à epidemia de HIV/Aids em particular, atravessam período crítico e desafiador no contexto social e político do Brasil no momento atual. O presente ensaio teve como objetivo discorrer sobre alguns desses desafios e os construtos conceituais que se julgam relevantes como recursos para seu enfrentamento. A reflexão destaca a resistência à biomedicalização, às abordagens individualizantes e ao abandono da perspectiva dos direitos humanos como grandes desafios do combate à Aids e discute como os conceitos reconstrutivos de vulnerabilidade, Cuidado e integralidade, desenvolvidos no ambiente da reforma sanitária, da conformação do Sistema Único de Saúde e da própria construção da resposta brasileira à epidemia de HIV/Aids, podem trazer subsídios relevantes para a resistência ao desmonte das conquistas alcançadas e à construção de novos caminhos emancipadores para a saúde coletiva.*

PALAVRAS-CHAVE *Síndrome da Imunodeficiência Adquirida. Direitos humanos. Vulnerabilidade em saúde. Integralidade em saúde.*

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The context we live in today is challenging. At the same time that we still have a long way to go to eradicate or at least control the HIV/AIDS epidemic, we are challenged by another devastating pandemic such as the COVID-19; and all of this in a scenario of social policies setbacks, of threats and constant disrespect to human rights, and in a wave of deleterious political conservatism. This scenario, which to a large extent is global, is particularly serious in Brazil although we have a not-so-distant but no less challenging perspective of contextual changes that bring us hope.

In the specific case of response to the HIV/AIDS epidemic in the country, despite setbacks and obstacles experienced in recent years, we have in our favor political, technical, and conceptual achievements that still leave Brazil in a privileged position in relation to other countries, and inspire and offer resources to insist on necessary reconstructions and, perhaps, facilitated by eventual changes in the political scenario. From the National Unified Health System (SUS), which has fully demonstrated its importance in the COVID-19 pandemic context, to the already tried models of partnerships between the state and Non-Governmental Organizations (NGOs), as well as conceptual references that have crystallized in the field of public health over the past four decades, we have built in Brazil a base to continue investing on the inspiring motto of the VIII Conference, that 'Health is a Right' and built a 'viable unprecedented', as Paulo Freire would say, a base that in the midst of such an unfavorable scenario allows us to insist on this ideal.

In this essay, I will concentrate on the conceptual aspect. Since the beginning of the HIV/AIDS epidemic in Brazil and in the wake of the SUS consolidation, managers, health workers, activists, policymakers, organized civil society, and the academic community have been building a series of concepts that express and systematize debates, reflections and actions resulting from the dialogue between different subjects in the field of practice, providing ethical, political, and technical horizons. I will call these concepts reconstructive because I understand that they are not 'inventions' in the usual meaning of the word, but they are rather based on pre-existing concepts and practices which, however, are reconfigured in new arrangements opening other horizons and possibilities for action. Concepts that, despite not having the best conditions for practical application at the moment, at least work as ways to resist the mischaracterization of the great civilizing achievement represented by SUS and the Brazilian response to the AIDS epidemic. They can serve as a basis to not lose sight of the adversities we need to face; at the very least, an alert to what must not be allow to happen in order to move forward again.

In this sense, it will not be difficult to realize that the 'biomedicalization' of the response to HIV/Aids is one of the problems we need to face. By this term, we refer to recent debates that broaden and requalify the discussion of medicalization developed in the 1970s. Beyond the tendency to pathologize and medication-driven approaches to health needs, biomedicalization refers to processes of subjectivity construction and conformation of behavioral patterns and sociability shaped by the exponential production and incorporation into health policies and practices of highly developed technologies for the management of vital processes through their biological substrate[1].

The critique of biomedicalization does not imply any kind of demonization of technosciences. On the contrary, technologies such as Post-Exposure Prophylaxis (PEP), Pre-Exposure Prophylaxis (PrEP), prophylaxes and drug treatments are welcome and are precious resources. The problem is the illusion that the mere existence of these resources will by itself solve the epidemic, disregarding fundamental aspects such as access, acceptability and effectiveness of these resources in the diverse and unequal daily lives of population groups – without entering the discussion of the rationality of the selection of resources to confront the epidemic in the definition of

priorities in health policies and the economic interests, and even the 'moral agenda' involved in these choices[2].

Another constant threat to be overcome, which often goes hand in hand with the above mentioned, is the individualization of the response to the epidemic. While on the one hand, proposals that value the freedom of people to choose the prevention and treatment methods that make the most sense to them in their particular life contexts and values are not unimportant, on the other hand, to ignore that the greatest autonomy will always depend on the intersubjective contexts in which people are immersed, largely determining their choices and possibilities of implementing them, is also to build another paralyzing illusion. More than that, it is a deeply unfair perspective, since various intersubjective contexts will limit the choices and possibilities of its implementation, so that to speak about autonomy to protect oneself from HIV/AIDS will sound almost like sarcasm. Not to mention the structural aspect which is already well known in the fact that every epidemic is born from the ways in which we collectively organize our relations with each other and with our environment, and therefore only collectively can we transform these relations in order to prevent and/or control them.

Finally, I shall highlight the aspect, already mentioned at the beginning, of the threat that the neglection of human rights represented by the neglection of human rights as a guiding perspective for interventions on HIV/AIDS, whether in prevention practices or in treatment or rehabilitation. Although we know the limits of this referential and how much its conception and language are still crossed by colonialist aspects (racism, ethnocentrism and several other forms of discrimination), it doesn't seem to be a normative reference more open to reconstruction and commitment to freedom, equity and human happiness for the proposition and evaluation of public health policies and actions.

By following criteria that directly compare techno-scientific authority with values that go beyond its territory of validity, that is, by submitting the 'how to' of the technique to the scrutiny of 'what should be done', 'what cannot be done' and 'why it should or should not be done' proper to the discursive domain of human rights, possibilities are open for the definition of non-biomedicalization and non-individualizing parameters for more public, ethical, politicized, and socially sensitive judgments for responses to the HIV/AIDS epidemic as to other challenges of health promotion and protection.

It is worth highlighting here three of these reconstructive concepts that seem important in an attempt to confront the above threats or at least resist their advance: vulnerability, Care (with capital letters to call attention to its conceptual intent, differentiated from a more ordinary, theoretically naive use) and integrality

Let's start with the concept of vulnerability. In a brief retrospective, let's recall that the concept first appears in the literature with some degree of systematization in the book 'Aids in the World', organized by Jonathan Mann, Daniel Tarantola and Thomas Netter, published in the United States in 1992, and later translated into Portuguese and edited in Brazil by Richard Parker, Jane Galvão and José Stalin Pedrosa[3]. The conceptual framework advances and is resumed in a more refined way in 'Aids in the World II[4], edited by Mann and Tarantola, not yet published in Brazil. Here the relationship between vulnerability and human rights is clearly addressed.

Besides the participation of Brazilians such as Herbert Daniel and Richard Parker in the process that generated the publications in North America, an initiative of the Global Aids Policy Coalition, the arrival of the concept in Brazil found a fertile moment both from the political point of view with the post-dictatorship democratic reconstruction in turmoil since the enactment of the 1988 Citizen Constitution, and from the techno-scientific aspect with important subsidies coming from collective health, from education

within Paulo Freire's perspective, from constructionist social psychology and from critical social sciences. At the intersection between a progressive socio-political context and an effervescent academic environment, a third mediating element was fundamental in this scenario: human rights. A driving element for social movements to demand effective and equitable policies to respond to the epidemic, the reference to human rights became a stimulus and a guide for the conceptual reconstruction I have been referring to[5].

All the criticism already formulated in relation to the preventivism, the 'banking education', and the behavioralist approaches in the field of health found in the vulnerability framework a powerful opportunity to reconstruct concepts applied to public health and prevention in the context of the years 1980s-1990s[6]. At the same time, contrary to global trends based on neoliberalism, in which the state was disengaging from social commitments, the health system in Brazil was reorganizing itself based on the premise of health as a right[7,8]. The country developed this notion and creates a unique, universal and free system at a time when services were being dismantled, or not investing in health worldwide. To this, add the experience of movements prior to the HIV epidemic that already pointed to this reconstructive tendency oriented in the perspective of human rights, such as the movement for comprehensive care to women's health and the anti-mental institution movement of the Brazilian psychiatric reform. All this has given the concept of vulnerability its own features in the country with repercussions on the international reception of this concept[9,10].

If in its original formulation the vulnerability concept and its relationship with human rights were developed mainly as an advocacy instrument, a key to identify inequalities and demanding accountability, in Brazil, much like our best 'anthropophagic' traditions (to use the metaphor that the Brazilian Modernist Movement adopted to express our way of incorporating and reconstructing foreign cultures), it takes on a more radical character and seeks to find the social and political roots of exposure to HIV infection and illness and its unequal distribution. At the same time, it seeks to be less an empirical-analytical knowledge of explanatory character, but is concerned with making comprehensive-interpretative syntheses that approach the particularities of the various social contexts and, in this way, assume the pragmatic character of enabling means to transform these contexts[11].

To summarize, we can say that the Brazilian framework of 'Vulnerability and Human Rights' as a conceptual construct seeks to build comprehensive totalities in which the dichotomy between the individual and the collective is refused, always articulating as closely as possible the three classical dimensions of vulnerability analysis – individual, social, and programmatic. Even regarding the individual dimension, the aim is to strengthen an understand that goes beyond the idea of a 'monad' subject, a cell from which interacts with the other cells in the world 'tissue'. Rather, it starts from the immediately interactional perspective of the construction of subjectivities, of individuals understood as living intersubjectivities always in the process of becoming. In this sense, it is impossible to think about the determination of individual behaviors and interventions on them without taking into account the interactions concretely experienced, always crossed by power relations, by institutional structures, by relevant cultural issues, especially those that we have been discussing in public health: gender, race and generation relations, among others.

Likewise, the social dimension is reconsidered as 'contexts of intersubjectivity', that is, as the dynamic structuring – cultural, political, moral, economic – of the interactions that constitute us as communities and individuals. In this sense, we seek to reconstruct the notion of identities: being a woman, or black, or an adolescent, or poor are elements that necessarily refer us to gender relations, race relations, generational relations, etc. Thus,

the ideal is that we abandon the very common expression 'vulnerable subjects' or 'vulnerable populations' and start using 'made-vulnerable populations' or 'making-vulnerable relations'. It will be more difficult, even from a phonetic point of view, to change the habit of referring to the interest of our analyses as 'vulnerable populations', but the truth is that in order to be rigorous with the adopted conceptual perspective, we should strive to do so.

Human rights are an important normative reference here. They make it possible to establish bridges between identity politics and social solidarity politics precisely because they show, through the experience of disrespect shared by an identity group, that benefits that should belong to everyone are, in practice, being the privilege of a few. At the same time, they allow these groups to contribute with new and/or different goods and values to debates on rights conceived from their particular situation which, even though they are not yet recognized as rights, they may be aspired to and should be met.

The programmatic dimension of vulnerability analyzes also implies the reconstruction of certain traditions in the health field. This is because policies, programs, services, and actions, in contrast to what is usual, are not targeted after situation analyses performed at their margins. What is already being effectively done is part of the situation analyses, and a programmatic element is not always beneficial, on the contrary, it can create vulnerabilities such as excessively medicalizing practices, little sensitivity to the singularity of people and their contexts of intersubjectivity, reproducers of stigmas and discriminations of gender, race, etc. For this very reason, the criterion for analysis of programmatic conditions cannot ignore evaluations about how much and in what way actions technically proposed for intervention are favoring or hindering the exercise of rights, or are compatible with them.

It is also worth noting that the three dimensions of vulnerability are only three viewpoints of a reality that is unique even though, in general, one of them is the 'gateway' to these analyses. It is not possible to account for the whole reality, but it is possible to focus on some aspects of it and be clear about the larger relationship of each dimension with the others. Schematically, when we try to understand the vulnerability of individuals or populations to HIV/AIDS or any other health condition, we must always be clear about which health condition we are dealing with - one is not vulnerable in general; one is vulnerable to something and in determining relational contexts and times. This is important so that we do not 'essentialize' the approach to vulnerability, making it an attribute of someone, a group or some situation. With this clear, we can look to epidemiology and other health sciences for resources to identify actions, situations and exposure that imply vulnerability. In this regard, it is worth highlighting the importance of epidemiology and risk analysis. However, the vulnerability analysis cannot stop there, it always has to consider the social aspects that allow understanding what the epidemiological associations indicate, as a kind of an iceberg tip. Here comes the fundamental interaction with the human sciences as it brings elements to think about these structural aspects, practices, and intersubjective contexts that are at the base of situations of vulnerability.

The interaction with practical knowledge, the knowledge people involved in the situations we wish to transform, already have about their problem and how they manage it in their daily lives, is as important for the aspirations of vulnerability analysis as the interdisciplinary mediation between scientific knowledges. This local and everyday knowledge is essential to understand what happens in concrete and what generates vulnerabilities. The social sciences have already been pointing out the importance of intersectionality between the various social markers of difference (gender, race, social class, etc.) to understand the structures and dynamics of social relations which assumes special relevance in the field of health[12]. Such transcultural and diachronic categories will

have greater potential for understanding their realities as the experiences lived and reflected by people in their various contexts give them and the intersectional effects their local colors and features. For this reason, the participation of the subjects immediately concerned, those in a situation of vulnerability, is fundamental both for the formulation of knowledge and for its application in the field of HIV/AIDS and other health situations to which the vulnerability framework applies. The application of human rights principles in the health care organization also depends on this involvement to avoid such principles becoming more speculative than pragmatic. How to evaluate the acceptability, access, accessibility, quality, and effectiveness of actions without the testimony and participation of the beneficiaries of these practices?

In this way, we enter the third analytical dimension of vulnerability: the programmatic element. Here, the attention to biomedicalization and individualization in its alienating and excluding effects demands care and help from the human rights framework as a normative criterion. Beyond the proven technical effectiveness and scientific grounding of intervention actions, in every decision made here, one must reflect on the choices of strategies, actions, and resources that will be deployed. Which rights, what are their scope, and to what extent are they or are they not being respected, promoted, protected, and equitably distributed in the construction of responses to the HIV/Aids epidemic?

The second reconstructive concept, which is related to the third dimension of the vulnerability analyses discussed above, is that of Care[13]. In fact, it is useless to seek paradigmatic changes in situation analyzes to understand and face the problem of HIV/AIDS, or any other health problem, without also thinking about the transformation of health work processes.

Fundamental to resisting the strictly biomedical and individualizing reduction of HIV/AIDS prevention and care is to overcome the objectifying tendency about the beneficiaries of health actions and the correlative instrumental reduction of the interactions between professionals and users of health services. It is necessary to overcome the traditional conception in which a health professional holds technical-scientific knowledge that will be applied to patients to produce an objective interpretation for intervention. In this approach, people's practical knowledge remains at the margin of the process, sometimes even understood as noise and not as necessary knowledge capable of revealing the determinants of the problem to be prevented or treated, and the practical implications that can give meaning and effectiveness to the proposed technical actions.

The concept of Care seeks to value the intersubjective aspect and the practical sense of the encounters between professionals and the receivers of health actions. Those who care and those who are cared for are understood here as subjects in their full sense, bearers of their own aspirations and knowledge which, however, can merge horizons in a common interest for the construction of health. Both possess techno-scientific knowledge and practical knowledge which in different proportions and with different meanings take part in Care – although in this relationship we health professionals mobilize a greater content of techno-scientific knowledge, in the same way that the receivers of health actions are expected to participate more actively with their practical knowledge. An object co-constructed between subjects in the interaction between diverse and necessary knowledge: this is the idea of Care. The reconstructive concept of Care aims at formulating care that does not disappear with the subjects, that neither reduce the health professional to an uncritical and mechanical applicator of techno-scientific knowledge nor reduce the demander of care to a medicalized object. It also aims not to ignore the affective, emotional, social and contextual aspects that are before, during and after the caregiving encounters accessible only in the voice of its subjects.

These different voices in interaction will allow a deeper and more fruitful relationship between the perspective of technical success of health actions, that is, the positive effects sought by the application of techno-scientific knowledge and the horizon of practical success meaning, in fact, what will make sense to people, responding to their needs in everyday life. In other words, we seek in this dialogical encounter to develop work processes that articulate technical and practical success taking as their normative horizon the happiness projects of people, populations, and identity groups; work processes oriented to what moves people, what is effectively important to them, to what they want to build in their lives. This is always thought of as a singular existential project, but always relational constantly understood from the different situations of subjects in their contexts of intersubjectivity.

The health sciences have much to contribute to the projects of happiness that we build in sharing, but as pointed out, when discussing vulnerability, the social and human sciences and practical knowledge are also crucial here. Moreover, it is impossible not to recall, although this subject should not be further developed here, the necessary exercise of practical wisdom. We humans are beings endowed with the capacity to choose. In health it is no different, although the scientific basis of its practices sometimes gives the illusion that they do not depend on choices. In health care we are all the time making technical choices that have ethical, moral, and political implications[14]. Moreover, for these choices, there are no rules, no law, no regularity that allows us to know in advance everything we need to act and the outcome of our decisions. Our scientific knowledge allows us to anticipate and control part of the instrumental effects of our techniques, but it does not allow us to assure which will be the most virtuous decisions about what to do, that is, those most capable of responding to the happiness projects of those we care for. The only way to do this is to seek dialogically constructed paths in the spaces of practice and to rely on the practical wisdom accumulated in normative horizons that are also open to the dialogical construction of the common good even if with limits as we pointed out above: human rights.

Furthermore, this dialogical perspective of Care reminds us that any caring interaction will always be produced in contexts of intersubjectivity and that this involves the 'micro' and the 'macro' dimensions of these contexts. It embraces the question of interpersonal relationships: what is the best way to reach people, to produce effective and symmetrical dialogues among those involved in health work processes. However, the possibility of these dialogues happening also depends on macro-structural aspects: how is it possible to think of Care, of full subjects meeting and building together health actions if there is no health system which allows universal and equitable access to these actions? So, although the concept of Care and its dialogical basis tends to refer us more easily to the interpersonal aspect and to the relationships between professionals and receivers of health care actions, we cannot underestimate the importance of its reconstructive appeal in macro-structural plans as well. In this sense, the SUS proposal needs to be understood (and defended) as a potent public Care action[15].

In conclusion, I refer to the concept of integrality[16,17], which I also call reconstructive. Like the concept of Care, the concept of integrality was not a specific product in the response to the HIV/AIDS epidemic. It was formed with the Health Reform, with the SUS proposal, and consists of one of the principles of that very important tripod, together with the principles of universality and equity, a principle without which the other two make little sense. It doesn't make sense to have a health system with a wide offer of services for a few, or universal access to only a minimum package of services as the World Health Organization (WHO) has proposed; in the same way, it doesn't make sense equal

access to health actions for people with different needs and contexts, equity is fundamental. Still, if we consider that people do not have only occasional health demands but they live health-disease-care as a continuous and ongoing process in their daily lives, then it is necessary that health practices have flexibility and dynamism capable of responding equitably and universally to the diverse and complex demands for promotion, protection and preservation of health.

In the international debate, 'our' integrality tends to be perceived as equivalent to comprehensiveness, denoting a health care that reintegrates in the particular case of each individual care what the specialization process has pulverized among health professions and specialties. Although this integrating attitude is not unfamiliar to our conception of integrality, and is also part of it, among us this principle ended up extending beyond this clinical space. In Brazil, integrality also implies structural aspects of the organization of services and the composition of care models.

This extension and its relation to the process of the SUS implementation with interface between social movements, managers, and academics have made the concept of integrality complex and difficult to grasp in a single definition. The most effective conceptual approach to this principle seems to be to address it according to some axes around which the idea of integrality was being generated and developed in the plan of practices interpreted here from the theoretical perspective of the work process in health[18].

The first of them, the plan of needs refers to overcoming the restriction of the interpretation of what people need in terms of health to categories pre-set by medicine or the more traditional health sciences. Here the proposal is to incorporate richer and broader interpretations. It is to bring to the core of health care diagnoses based on the detection of vulnerability situations and human rights violations, instructing practices to reduce vulnerabilities through individual, community, and/or structural actions.

The second axis corresponds to the purposes of the work processes. Here, in addition to the more traditional sense of incorporating practices ranging from health promotion, disease prevention, treatment of illnesses, rehabilitation and terminal care into the range of actions offered by the health system, it refers to the need to not only juxtapose these offerings, but to integrate them in a way that makes practical sense to those people; to build arrangements between these different types of action so that their potential for technical success can be effectively articulated with the motivations for practical success in the different contexts and situations of the recipients of health actions.

To improve the assessment of needs and to respond to them with comprehensive and integrated purposes – and this is a great challenge for HIV/Aids control programs – what we call the articulation axis becomes fundamental. To actually respond in an integral way to the needs and purposes as described above it will be necessary to work in teams and with synergies among various levels of care in the health sector and several other sectors beyond health. In Brazil, we live in the challenging situation of decentralizing the formulation of policies and actions to fight AIDS, so that the diverse contexts of vulnerability can receive deeper and more particularized perceptions of needs and pertinent actions at the same time that one seeks to build articulations between professionals and sectors that can hardly be available in the scale of decentralized services. Such articulation depends on building care lines, assistance networks and service consortiums that face not only cultural barriers, arising from the dynamics of the different territories and their forms of sociability, but also from political parties and power disputes within the various municipalities.

Finally, the axis of interactions. This is perhaps the most basic and difficult axis of reconstruction related to integrality. This axis is related to the construction of effective dialogue in health care interactions, an

aspect that has also been worked on by humanization policies. From the perspective of humanization, proposals are often excessively attached at the local level, to the issue of good interpersonal treatment, and the development of empathy between professionals and service users despite the National Humanization Policy being much more radical in its propositions. In the perspective of integrality as a reconstructive principle of the work processes, the great challenge is to create technological arrangements and processes that stimulate the presence of different individuals and the production of such contexts of intersubjectivity between professionals and recipients of health care and among health care workers that allow an effective co-construction of Care actions, with rich and contextualized needs and with diverse and pertinent actions from the practical point of view.

In summary, I would like to emphasize the importance of the experience of the development of responses to the HIV/AIDS epidemic in Brazil in its synergy with the consolidation process of the SUS. This was a source of motivation and subsidies for the theoretical exercise of improving means and ends in the understanding of the social determination of health-disease-care processes, not only in the specific context of HIV/AIDS but also for health practices in general. On the other hand, I have tried to point out the relevance that reconstructive conceptual frameworks can have for a supportive return to the practices, in order to strengthen the achievement of the ideals from which they originated. However, it must be noted that this generous and creative richness of practices and their corresponding conceptual constructs are not immune to setbacks and destruction. History shows us that emancipatory achievements are not definitive and that their values are always in dispute. The lived experience in Brazil in recent years could not give us a more tragic and eloquent testimony of this. Therefore, from both practical and theoretical points of view, in the AIDS field as well as outside it, there is no more urgent challenge than to resist violence, intolerance, and authoritarianism; and to move forward, not to fear, to insist on practices and concepts, to jointly build a new reality according to our best and most democratic emancipatory values.

Collaborator

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