

Pemphigus: cartography on the coordination of health policies

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Abstract *Pemphigus is a group of autoimmune blistering diseases that affect the skin and mucous membranes, the global incidence of which is 0.75 to 5 / 1.000.000 cases a year. The approach taken derives from the relations of power/truth and subjectivity that produce modes of experience from the perspective of hospitals and public policies. It involves cartographic qualitative research, supported from a Deleuzian standpoint. The objective was to discuss pemphigus as a chronic disease and discuss health policies and their impact on care practices. This cartography was conducted in a philanthropical hospital, which is a national reference for the treatment of pemphigus. The research was conducted from September 2012 to February 2013. The analysis of materials included: medical records, field diary reports of all healthcare activities, such as medical consultations, technical procedures performed by nursing staff and medical staff and reports of patients, families, physicians, and nursing staff. The analyses were created from a Foucauldian historical and genealogical perspective. The conclusion reached is that health policies for chronic patients with pemphigus are not presented as a condition to be avoided / prevented, but as abnormal groups and bio identities that have no effect on the whole population.*

Key words *Pemphigus, Cartography, Public policy*

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Introduction

Pemphigus is an autoimmune disease manifested by the appearance of blisters on the skin. The population at risk for the disease consists of rural workers, people who live and work in an endemic area. There is no predominance of gender, racial or ethnic group. It affects children and young adults, with a peak incidence between the second and third decade of life. The affected population lives in rustic homes, 10 to 15 km from large rivers or inlets, and the disease can affect several members of the same family. Currently, pemphigus is endemic in certain Brazilian states, with predominance in the Midwest region, and so far its etiology is unknown¹.

There are two more common clinical types of pemphigus, vulgaris, and foliaceus². In pemphigus vulgaris, acantholysis occurs in the basal layer, and can affect the skin and mucous membranes; it is clinically the most severe form, with a worldwide annual incidence of 0.75-5 / 1 million cases. In pemphigus foliaceus, acantholysis occurs below the corneal layer, that is, more superficially, rarely affecting mucosa^{2,3}. The standard variant is relatively rare and occurs more frequently after the age of 40, affecting both genders.

Pemphigus foliaceus has the same epidemiological characteristics of *P. vulgaris* in all parts of the world. However, in Brazil, it has distinct endemic epidemiological aspects, with high frequency in the rural area of some Brazilian states. It also has a probable genetic connotation, with a family frequency of 12% of the cases². Existing research on the subject is limited to epidemiological analyses and pharmacological management techniques.

However, in this study, we will seek to favor the articulations of pemphigus in the field of public health policies for patients with pemphigus, a field where unfortunately research and political initiatives are scarce. This field of analysis allowed the construction of tools that guided the course of research not to seek evidence but instead questioning the political relationships in health and pemphigus.

We believe that this study may contribute to the foundation of future perspectives, guiding public health care to patients with pemphigus, besides favoring the production of new research questions.

Methodological route

This is the contour of qualitative research using a cartographic methodology, supported theoretically from a poststructuralist perspective of social psychology. As a methodological guideline, we used cartography proposed by Gilles Deleuze, because, in this method, we understand cartographic research as a performative practice, that is, performed with the other and not on the other. This shows that to understand what it is like to live with pemphigus, it is necessary to follow this process in action, in the daily practice of people who experience it^{4,5}.

Cartography derives from the theoretical efforts of authors Deleuze and Guattari⁶, who worked the construction and deconstruction of specific forms of thinking the structures of knowledge, presented in the perspective of the multiplicity of acts and facts and traversing the recognition of rhizomes that are conceptualized as the process the construction of human knowledge, seeking the potential of difference^{5,7}.

Gilles Deleuze shows the attitude of cartographic research as something territorial and collective. We have a collective attitude because it is relational; it is political because it involves interactions between forces; it has to do with ethics, because it stems from a set of criteria and references to exist; and it has to do with aesthetics, because this set is established through it, representing relationships ways of expression, a way of shaping the existential territory itself. Therefore, it can be said that cartography is a study of the relationships of forces that underpin a specific field of experiences, which is mediating between users and health professionals, institutions, clinical procedures, diagnoses, territories, etc.^{7,8}.

Faced with such a process, we place ourselves in the position of a cartographer in the field of intersubjective health relationships. The existential territory we traversed was a nonprofit hospital, in the dermatological unit of national reference in the treatment of pemphigus in Brazil. Performing such activities for over 60 years, said hospital is located in the city of Campo Grande, Mato Grosso do Sul.

We provided four 6-hour weekly meetings for territory ambiance and acculturation from September 2012 and February 2013. During and after this period, we held monthly discussions to construct the analyses between a group of graduate peer reviewers and doctors with expertise in cartographic research, so that, to this extent, we could expand the possibilities of observation,

meanings, and mediations for the construction of “rhizomes”, seeking the potential of difference. We aimed to question pemphigus as chronic disease and discuss health policies and its repercussion on care practices.

The analyzed materials were medical records, field diary reports on all care activities performed, such as medical consultations, technical procedures performed by the nursing team and medical staff, as well as reports of patients, relatives, physicians, and nursing staff. Thus, we obtained a mixed sample of participants, namely, two dermatologists, two nurses, six nursing technicians and eleven patients diagnosed with pemphigus, totaling 21 participants.

More than 90 (ninety) meetings were held during this 6-month wetting and acculturation period. Before this period, we submitted our research objectives after signing an informed consent form. Such relationships with patients and staff have been in the construction of bonds, since we permeated the territory of experiences, observing and mapping the relationships established between patients, nursing staff, and physicians. These observations and dialogues were mediated informally, that is, without a previously established script.

This path has led us to thematize about the existential becoming of pemphigus – an existential becoming, as Deleuze and Guattari⁷ would put it; it is a matter of casting our sight on a whole system of production of senses and meanings that delimit the experience of having/being pemphigus – this attitude led us to theorize three cartographic perspectives, after analyzing all the collected material, as follows: Pemphigus: first evidence, Pemphigus: constructions and existential practices and Health policy: pemphigus as investment surface.

Results and discussions

Pemphigus: first evidence

We would like to ask the reader to try, in a way, to elucidate some questions regarding the life trajectories of the subjects of this study.

In our meetings in this territory of existence, we can analyze that the doctor’s questions, the patient’s discourse and the observations conducted in these relationships end up building a “being pemphigus”. How do they stage it? We will show in a generic way how this experience and its first indications occur.

The patient in his first consultation refers to blisters that he thinks are of impetigo (cutaneous disease of bacterial origin), *but this blister hurts like a burn* (P9), they manifest in the trunk, face, scalp and over time arise in the upper and lower limbs. After these symptoms, patients seek the services of a basic health unit near their home. In some cases, anti-inflammatories are prescribed, *but this medicine did not help at all there at the health post, they do not know what it is that I have* (P3). He realizes that lesions and aches and pains increase when he is exposed to the sun, *I had to stop working, I am a mason, I stay under the sun all day, it really hurts* (P4). If the patient is not quickly diagnosed, he endures fever systems and blisters grow and spread in other places. *I thought I was going to die, it made me shiver, I took that stuff to lower the fever, but to no avail* (P3). At this stage, patients return to the health service, which ultimately refers them to hospital service. After many weeks, this patient is referred to a specialized service. *I stayed a long time without knowing what happened to me; nobody knew what I had for sure* (P5) All this course is accompanied by restlessness: “What is it that I really have?”

Moreover, when arriving at a specialized service, the biomedical answer can be inscribed through a set of visible symptoms, with complaints that can be articulated by a patient. This clinical performance of the pemphigus will have to be outlined. Thus, the question out there is not what pemphigus is, but how specific practices produce it. Regardless of the answer that can be drawn, if the question is asked, what happens when we observe this realm of practice is that pemphigus seems to occur in many different ways.

Three of them are described here, as revealed by the authors, who inscribe pemphigus under visibility plans. When monitoring the diagnostic and hospitalization procedures, one can perceive all the biomedical technology employed in this body⁹. First: at a clinic, a patient complains of blisters, which, when bursting at the slightest contact, cause pain similar to that of a burn. Does the doctor want to know more about when and how the symptoms manifest? Then he approaches the patient, analyzes his skin: what is the size of the lesions? What is the site of lesions? Is there any bleeding? Alternatively, infection? What is the general appearance of the skin? We note Nikolsky’s sign – which consists of the epidermal detachment of perilesional skin after friction. We have here a complaint that is permeated by a biomedical knowledge for the construction of the clinical diagnosis.

Also, where can we assign the possibility of a relationship that allows the personal expression of experiences? Anxiety, social isolation, fear, senses associated with an aesthetic perception of “deformity”. During one of the meetings, (P6) says: [...] *after I got married I had the blisters, I felt deformed, I was afraid that my husband was going to leave me, I was afraid to leave home, I had never said this before, nobody ever asked me.* We have seen that pemphigus, while knowledge about the autoimmune disease, also represents a biological identity conflict, where the body “deconstructs” the body itself, where blisters are inscribed on the place where our identity is deep-seated: the skin. Such possibilities of expression are hardly possible, and we note in this measure a system that, similar to other health care systems, is limited to the bracket of diagnoses and pharmacological management measures.

The second perspective revealed is about laboratory routines. It is known that means of histopathological and immunofluorescence techniques can diagnose pemphigus, showing the presence of IgG antibodies, both in the skin and the blood circulation of pemphigus patients, directed against the intercellular spaces of the epidermis¹⁰. We follow-up these tests and the IgG normality/abnormality indexes are compared, and the diagnosis is drawn. Patients are not admitted to hospital without this diagnostic tool being used. Thus, biomedical know-how establishes knowledge and life concerning being / having pemphigus, where subjects are only traversed by these practices. We perceive these relationships in the statement of (P5) when he says: *Well, a piece of my skin went to the lab, the nursing girl came here and told me that she had to take me to the lab. They collected some stuff and then they confirmed it was indeed Pemphigus.*

It is thus understood that having pemphigus is not something that a person is in itself, but something that it becomes when articulated in specific practices, mostly inscribed on biomedical knowledge.

So then we have the third perspective, namely, the socioenvironmental aspects. Studies show that there are possible environmental agents in the involvement of Endemic Pemphigus Foliaceus. One of them is the relationship with the sting of black flies called *borrachudos*. In one of the earliest epidemiological studies of the “Wild Fire” Cooperative Group, it was reported that Simuliidae stings were 4.7 times more frequent in individuals with Endemic Pemphigus Foliaceus than in controls. The *Simulium nigrimanum*

was detected as being the predominant species in a high EPF¹⁰ prevalence area.

These studies report that exposure of the patient to other environmental factors, such as other hematophagous insects (triatominae and Cimicidae) and rustic dwellings, with thatched roofs and adobe walls, are relevant in the onset of Pemphigus¹⁰.

The characterization of the socioenvironmental identity as a record about the body seems to be established in this group. We observed that, in all the first visits, the survey concerning the place of residence was one of the items that underpinned the diagnosis described in the medical records. We noticed that all the individuals diagnosed with pemphigus were residents of rural areas, endemic to pemphigus, and they were: farmers, bricklayers, carpenters, and homemakers.

Therefore, in this third performance, we investigated the production of a possible “eco-identity” or “Oikos-identity”. *Oikos* is a Greek word whose literal translation into Portuguese means “home” and gives rise to the prefix “Eco” of our language, or regarding existential territories, a possible “home identity”.

Moreover, this body of personal estrangements, of unclosed skin, protrudes socially into a “home” register, not only of a home as the dwelling place, but also an identity-related dwelling, its skin, and its body. This skin that retains contains in its internal and external characteristics several “footprints” of relationship, whether they originate from a clinical, laboratory or socio-environmental inquiry. As Deleuze¹⁰ tells us, “the inner and outer sphere, the deep and the high dimension have no biological value except for this topological surface of contact. It is, therefore, even biologically necessary to understand that the deepest is the skin.” This subjectivity takes place in the relationship of forces that traverse the subject, in the movement, the meeting point of the practices and the self-recognition ways. Pemphigus as experience appears as a body that is biologically or dermatologically open to the “outside”, where the body threshold is invaded.

These three pieces of evidence end up building experience of being/having pemphigus not only anchored on a clinical, statistical or socio-epidemiological materiality. This information poorly guided knowledge on pemphigus.

We noted that this body that speaks more about an existence aesthetic realm, of the body as surface plane and social contact, of confrontation, where clinical and epidemiological practice no longer meet the demands of a human being

with interdependent needs, who says: *Nurse, am I going to die today? ... nothing will change that reality, living in a hospital and locked at home with fear of everything is not living!* (P10). It is considered, therefore, that this human being speaks through an existential practice with pemphigus, something that was transmitted to him as the unquestionable truth about his life, since the possibilities of life and being are anchored under a limiting knowledge of disease existence.

Pemphigus: constructions and existential practices

We sought to present a fundamental step for the aesthetic understanding of pemphigus, that is, an existential territory, as a construction of a multiple reality of the disease that is made and situated historically, culturally and materially⁹.

However, for such a meeting to be pursued, it is necessary to start from practice, as a set of relays from one theory to another, and the theory about a relay from one practice to another. No theory can develop without finding a wall, and it takes practice to cross the wall¹². Conceptual Foucaultian tools such as truth, power, and subjectivity that produce an aesthetic of existence, but also the living governing ways, are revealed in this practice of thought to map with pemphigus patients; these elements will be used to “cross the wall”, as Foucault tells us¹².

These conceptual tools allowed us to delimit such Foucaultian references, as far as the truth is concerned, presented as “inseparable from the uniqueness of the event”¹³. That which is qualified as true does not dwell in an *already there*, rather, it is “produced as an event in a specific space and time.”¹³

The discourses produced by these power relationships in the hospital are articulated in the patient’s statement, as follows: *I can no longer do what I want, I cannot eat what I want, or else the disease attacks. The doctor said that I have to do this to get well, so I’ll do it, right, what choice do I have? I’ll try to get over this* (P3).

Such statement is produced because, during hospitalization that takes on average 30 (thirty) days, patients were medicated daily with steroids, especially prednisone. One of the effects of this medication is increased appetite. The above statement is articulated through a biomedical power/knowledge practice performed by the nursing team, which prohibits excessive food consumption, using the discourse: *the doctor said [...]*.

In this respect, healing practices can be shown as a field of biopower, an unfolding of somatiz-

ing modalities of subjectivity, as we have resorted increasingly to explanations that emphasize biological characteristics of human behaviors and attitudes¹⁴.

When we refer to biopower strategies, we start talking about ourselves and act with each other on the assumption that biology preponderantly shapes our characteristics, but above all, this biopower, by which we are called in will deal with an investment in life, the ways of living and disciplinary and regulatory technologies that find a privileged focus of their investment strategies in the biological realm¹⁵.

Such marks of biological investment are unveiled upon hearing from a nurse. *You know, I have patients here who have had the disease for more than ten years, and have recurrence every time. I don’t think they follow the instructions at home, and I don’t think they take the medication correctly. Most of the hospitalized patients have been here before, but they do not seem to learn.* (E2)

This scientific visibility is made on the body [...] *do not seem to learn*, with pemphigus blisters that are inscribed on the skin as pathological marks, and are shown as truths about diagnosing and treating this body, which will be subjected to healing practices that have been “validated” again by medical practice.

Therefore, this analysis includes the power relationships established in the institutions, be it in the family, hospitals or school, marked by discipline and by norms, subject to politically submissive healing practices¹².

However, we also sought the production of a making-living, a way of regulating the life of the population as a whole. This regulation occurs in the body that is “classified” by an epidemiological questionnaire and will be carefully isolated in an inpatient unit with other patients with the same disease, where the political and healing practices will be controlled, whether in the diet, rest, length of hospitalization, dressing type or use of medication¹⁶.

With this broad meaning, the policy, that is, this dynamic modeling process, as characterized by Mol⁹, is the type of human activity that, linked to power, establishes subjects in relationships, coordinates them according to rules or norms that are not necessarily statutory and legal. No longer exclusively thought of a power center (the state, a class), the policy is also performed in local arrangements, by micro-relationships, indicating this micro-political realm of power relationships¹².

And in these self-constitution practices, we need to walk on some historical-political clues in

medicine and health, since the reflection of these truth effects on pemphigus begins to be expanded in this cartography, where these constructions of performances were also facilitated through a biomedical discourse that was produced culturally and historically within the scope of public health policies.

Health policy: pemphigus as an investment surface

During this construction of knowledge with patients with pemphigus, through his impressions on the public health system, a doctor from the service tells us: *there will only be public interest when the disease affects most of the population. When they are in the UBS, they do not receive Prednisone from the government, which is an essential medication for this treatment. In many cases, we have to resort to the Public Defender's Office so that patients can have access to medication free of charge* (M1). He says the treatment strategies available in the public health network were not compatible with the clinical needs of the patients and sometimes it was necessary to resort to legal bodies so that the cases could be dealt with. Thus, it can be understood, through such statement, that there will be interest when the economic processes are affected, that is, only when the disease begins to interfere with the production of the population. Also, when we do not have medical, pharmacological, and technological subsidies that tell us the truth about pemphigus, should we let these people die?

Through a poststructuralist analysis, we can consider public health as one of the responsible for the construction of a new urban structure, the production of preventive strategies and internalization of responsibilities over the body. It is undeniable that its different discourses are based on medical naturalism, which, by invoking scientific knowledge, legitimized the growing medicalization of the social space, that is, we must combat epidemics and endemics, scrutinizing urban space with health devices, and established itself as a dominant public health strategy.

Epidemics represented the privileged field for the production, reproduction, and diversification of medicalization in the social realm, with the corresponding strengthening of medicine power. However, the scientific assertion of the naturalistic discourse of medicine has always placed between brackets the political realm of health practices. In the name of the discourse of science, practices of marginalization of different social segments are justified¹⁷.

Many patients using the public health system ended up feeling marginalized when access to health was impossible for them. *No one knows how to treat my illness in my city, they have no medication, the doctor doesn't know what to say to me at the post, he just says I should do what hospital doctors told me to do, that's it! We're nobody there* (P8).

We note here a practice of the right to live and let die; it is evident that knowledge about people is essential so that strategies can be created to establish forms of government. However, the government that shows itself to this patient is one that limits access and inscribes this subject in a place of marginalization, since it does not respond to the epidemiological profile that can be attended to in a basic unit. In this practice, poverty, danger, and epidemiology relate to one another.

We note this condition of letting people die in the patient's statement that says [...] *they don't give the medication* (prednisone). *I became very sick, and I had a skin infection. They almost killed me* (P2).

This declaration refers to the power over the population exercised by the security devices that are produced by biopolitics and as a way of governing over others that are exercised through government technologies sustained by the production of biomedical knowledge¹⁸.

Thus, the concept of governmentality presented by Foucault¹⁸ is a critical instrument of a society managed by neoliberal ideals, acting on the population through security devices that limit and control their choices, desires, behavior, mobility, health, food, and finally, the life of individuals.

Let us use the definition of the Ministry of Health¹⁹ that considers chronic disease as cardiovascular diseases, neoplasms, chronic respiratory diseases and diabetes mellitus to have a broad understanding of the healthcare processes of people with chronic diseases. Also included in this list are diseases that contribute to the suffering of individuals, families, and society, such as mental and neurological disorders, oral, bone and joint disorders, genetic disorders and eye and hearing pathologies.

It is noted that the Ministry of Health¹⁹ includes the notion of "... diseases that contribute to the suffering of individuals, families, and society ...". We analyze in this section the conditions of this biopower that, through a biopolitical strategy, justifies the existence of control practices of individuals and the population in the name of people's "common good", health and vigor. Such

declarations refer us to a societal project, that is, a way of living, of who can live and how²⁰.

This type of government practice sometimes controls life or excludes specific living from the rationale of the functioning of society itself. Agamben²¹ presents us with a new paradigm of government, the State of Exception. To think of this State of Exception as a paradigm of government, he starts from the idea that, at present, the government is always exercising exceptions, and in this exception, it suspends the norm by arbitrarily asserting its authority. As reported by M1 *we have to resort to the Public Defender's Office to enable patients to have access to medication for free.*

This knowledge permeates Western politics and finds, in modernity, its maximum saturation. Its political-philosophical reflection is established in a clear correlation between the practice of the sovereign and the exercise of government in the modern state; such knowledge is identified when faced with the enunciation: *there will be only public interest when the disease affects most of the population [...]* (M1).

In this pemphigus cartography, the Strategic Action Plan for Coping with Chronic Noncommunicable Diseases (CNCDS) was accessed in Brazil. It is a plan that will have a 10-year period of investments from 2011 to 2022, which portrays such biopolitical phenomena¹⁹.

The Ministry of Health manual¹⁸ shows that the direct costs of the CNCDS to the health system have an increasing impact. In Brazil, CNCDS are among the leading causes of hospital admissions. A recent analysis by the World Economic Bank estimates that countries such as Brazil, China, India, and Russia lose more than 20 million productive life years annually due to CNCDS. Estimates for Brazil suggest that the loss of work productivity and decreased family income resulting from only three CNCDS (diabetes, heart disease, and stroke) will lead to a loss in the Brazilian economy of US\$ 4.18 billion between 2006 and 2015¹⁹.

Interventions for the prevention and control of CNCDS include some actions that have been monitored and evaluated through several studies, but while analyzing health policies, it is common to find that terms are inherently statistical, strategies are drawn through the relation of economic impact, feature of a biopolitics. However, where do other subjects that are not justified by the economic or epidemiological impact of their experiences stand?

I took leave from work. I am a farmer, I work for a company, and the limit of my certificate was exceeded. I had to go to the Social Security Office

(INSS). After 30 days, my dermatologist said I could not work, otherwise, the blisters could increase and hurt more, but the INSS expert doctor said I could indeed work, so what can I do? I'm going to starve. My wife is working for now, but when things run out, I cannot starve myself (P8).

Pemphigus, as an epidemiological phenomenon, does not have the same population expression as diabetes, cardiovascular diseases, among others, but we have experiences that must be addressed in this life reality, and these practices acquire intervention contours in all health care spheres.

Similarly, the World Health Organization (WHO) has issued the most cost-effective interventions, some of which are still considered the "best commitments" (actions that must be implemented immediately to produce accelerated results concerning saved lives, preventable diseases and avoided high costs)^{22,23}.

All of these "best commitments" planned by the Ministry of Health for CNCDS are illustrated in the slogan of the Federal Government's Online Portal, whose image is made up of an umbrella made with the national flag, "protecting" against several chronic diseases.

This protection will be provided, if you take care of your body, staying healthy because doing so will avoid diseases like diabetes, hypertension, obesity, and so forth²⁴. However, my question is: "When is CNCDS autoimmune? Am I under the umbrella of public health policy that should ensure my access to health?"

The rationality of perfect health leads us to believe that a body outside the patterns of self-control derives from a lack of self-management. *When I said I had pemphigus my sister asked me: What did you do? Is that contagious? So now, will I be able to visit you? She spoke as if I were a leper. (P2)*

When analyzing the Strategic Action Plan for CNCDS, is it appropriate to have a discussion that correlates with the possibility of making live for those preventable epidemics/epidemics: but what about those in which this is still not possible? They become ghosts, invisible to the field of public policy for investment in life, as Foucault says, "a life of the infamous men", who will not have the protection of the "umbrella" of health policies^{25,26}.

The Minister of Health¹⁹ emphasized that the CNCDS coping plan aims to promote the development and implementation of effective, integrated, **sustainable** and **evidence-based** public policies for the prevention and control of CNCDS and their risk factors and to strengthen

health services for chronic diseases. The plan addresses the four major groups of diseases (circulatory, cancer, chronic respiratory and diabetes) and their common modifiable risk factors (tobacco and alcohol use, physical inactivity, unhealthy diet, and obesity) and defines guidelines and actions in a) monitoring, information, evaluation and monitoring; b) health promotion; c) comprehensive care.

This is a performance of health policy for whom pemphigus does not appear as a hazard to be avoided/prevented, but as an abnormality of groups that has no effect on the population as a whole, such as the infamous in history that only appear in those brief contacts with power, that is, when inside the hospital.

Concerning measures of access to the health system, we see patients who do not receive adequate care, who go on a pilgrimage to health units and hospitals without comprehensive care provided for their needs.

We found no strategies geared to this population that is articulated as a proposal by the state health secretariat; incidence rates and health care services are not related on any government basis. That is, patients with pemphigus are like “ghosts” in the system.

In the few opportunities in which he transcends the biopolitical diagnosis of the present, Agamben²⁷ reflects on the notion of “form-of-life”, that is, of a life that cannot be dissociated from its form, which can never be understood as bare life, because in its living, acts, and behaviors, it is never about simply mere “facts”, but always of “possibilities of life”, always and above all of the powers. No human behavior and form of life shall ever be prescribed by a specific natural voca-

tion, nor allocated by any necessity, but, although customary, repeated and socially obligatory, they always retain the character of a possibility, or, in other words, they always put own life at stake²⁷.

Final considerations

We must consider through this cartography new possibilities of self-establishment in pemphigus and the care of the subject with pemphigus, since, as we traverse these cartographic tracks, we move and begin to promote new ways of composing the relationship with subjects, new forms of constructing and producing another perspective and another ontological policy.

It is not only a censorship of practices produced on pemphigus, but the construction of an equipment designed to produce discourses, committed to saying all that is to be said, to make its truth emerge, not merely to condemn or tolerate the subjects, but to manage, regulate and operate care practices according to an optimal standard on these social minorities.

When traversing the trails with pemphigus in this cartography, we considered that subjection and individualization practices are inscribed on these patients, in a profile of bioidentity and eoidentities, whose characteristics are reduced to biomedical patterns of identity and are placed on the margins of adequate health care policies practices, since healthcare policies that should give access are limited to population standards.

Moreover, the skin as a physical element in this construction is recorded, as the primary experience, not only by the scars of pemphigus but by a common mark of existence.

Collaborations

DAR Silva worked on the design, analysis and final drafting of the paper and AG Bernardes worked on the methods.

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