



## Methodological contributions towards the study of health care production: lessons from a research study on barriers and access in mental health

Contribuciones metodológicas para estudiar la producción del cuidado en salud: aprendizajes a partir de una investigación sobre barreras y acceso en salud mental

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**ABSTRACT** This article presents methodological contributions and a conceptual innovation for thinking about the production of health care, stemming from a study on access and barriers in mental health carried out in the municipality of Campinas (São Paulo, Brazil). The study used a cartographic approach and, after an initial identification of the most complex cases (on the part of the teams of workers), adopted the users as guides to explore the different levels of production of their lives and to evaluate the possibility of forming a network of existential connections that produce life as a fundamental analyzer of access or barriers to care.

**KEY WORDS** Health Services Accessibility; Mental Health; Cartography.

**RESUMEN** Este artículo presenta algunas contribuciones metodológicas y una innovación conceptual para pensar la producción del cuidado en salud, a partir de una investigación sobre el acceso y las barreras en salud mental realizada en la municipalidad de Campinas (San Pablo, Brasil). La investigación utilizó el abordaje cartográfico y, a partir de una identificación inicial de los casos más complejos (por parte de los equipos de trabajadores), adoptó a los usuarios como guías para recorrer los diferentes planos de producción de sus vidas y evaluar la posibilidad de armar, o no, una red de conexiones existenciales productoras de vida como analizador fundamental del acceso o barrera al cuidado.

**PALABRAS CLAVES** Accesibilidad a los Servicios de Salud; Salud Mental; Cartografía.

## FUNDAMENTAL PROPOSITIONS

Two fundamental propositions have guided this work in terms of its construction within the field of cartographic studies, as understood by Deleuze and Guattari in the chapter “Rhizome” of the book *A Thousand Plateaus* (1).

The first proposition is the production of different meanings within evaluation processes in which those who research and those being researched are one and the same. To achieve this it is necessary to work with implication and affect as constitutive components of the research field and the production of knowledge. This process focuses on the confrontation between what is evaluated and what is produced as a double implication, given that the object of knowledge is the action of the researcher, thereby confronting the researcher with him or herself. This characteristic meant exposing worker/researchers to permanent processes of education (that is, to analyze their own practices) as a way of evaluating and transforming their work and themselves in action. Therefore, the research study operates as a subjectivation device upon collective bodies of action in the world of work and as a process of gathering the knowledge produced in this way.

The second proposition was expressed by our attempt to escape from the classic formulation of indicators typical of evaluative studies. We explored the possibility of identifying not only the barriers that could be captured by indicators proposed externally, but also barriers and definitions of access created by the builders of health care networks – either workers or users – themselves, based in their perspectives. The team decided to construct algorithms that would allow us to analyze the production of health care as unique ways of constructing networks of existential connections, which finally were our primary markers of meaning.

This notion of networks is not easily grasped, therefore its construction needs to be made explicit. These networks are the result of a dialogue between the micropolitics of living labor and the propositions of health care production with an unyielding defense of life (2) and certain experiences in the field of practices of anti-asylum struggles (3).

From a didactic point of view, the best way to understand this notion of networks is through what we already know about asylum care: it isolates, disciplinizes morally and medicinalizes those considered “mentally ill.” Throughout this process, multiple networks of existential connections are broken and another network of connections is presented as the only other alternative, as the most protective and controlled possibility.

We believe this “sentences” a person to live exclusively within networks of connections defined by putting illness at the center of production of a given life, thereby forbidding other ways of living that are not generated by that existential territory. In this sense, Franco Basaglia (4) argued that we should put the disease in parenthesis so that, in the relationships of production of life, other possibilities not based on this sentence to exist only according to a diagnosis can emerge. This is why he spoke of the necessity of psychiatric reform in the field of health care for the mad.

This path within the daily realm of healthcare to us means that the production of networks of existential connections directed towards – and even amplified by – a single organizational possibility, as in the case of a life defined by sickness, does not support the production of more life. We therefore see it as a barrier blocking the emergence of new meanings of life and living.

From this perspective we contemplate the production of new networks of existential connections, as will be explained in the description of the study, and how such production is central to a health care that defends individual and collective life, seeking to enrich all forms of life. Finally, we explore to what extent this is connected to the field of technological production in health of living labor in action (5).

To achieve this goal, we had to make innovations in research methodologies, as we wanted to comprehend the movements of users who, in their nomadism and encounters, construct networks of existential connections. We also wanted to understand the movements of workers who, in the micropolitics of their encounters, use mechanisms that inhibit or facilitate these connections.

Starting with its very design, the research required the construction of collective action with workers from the existing mental healthcare networks, assuming the micropolitics of living labor

in action as the territory in which this action is produced.

Therefore, it was fundamental for us to construct all together an ethic regarding the relationships necessary to sustain such a delicate study. In discussing the ethics of knowledge production, as a constituent tension between self-care and self-knowledge, great effort is required to establish that what is different about another individual is of interest to me. However, at the same time, it should be clear that the intention is not to put that other individual under analysis without the researcher also being exposed to the same analytic process.

Once again, operating in this territory with the flow of living labor in action required a set of tools combining all the elements available which made sense. We understood that the path of cartographic research had this advantage: it placed in action, in a process constantly being renewed, all of the forces of the different regimes of truth that try to burst forth into the territory of micropolitics.

## THE CONSTRUCTION OF THE STUDY AND ITS BECOMINGS

We suggested Campinas (San Pablo) as the field in which to analyze access and barriers in mental health, because this municipality has an extensive and ample health care network. This network was a pioneer in the production of certain therapeutic mechanisms directed toward the principles of the defense of life. Due to its quality and sophistication, this network was for us an excellent scenario in which to analyze the issues of barriers and access; in other contexts we could be analyzing obvious situations determined by lack of options.

This article is the result of a study carried out between 2008 and 2011 called *Acesso e barreira em uma complexa rede de cuidado: o caso de Campinas*, to meet the joint requirements of the Health Ministry and the Science and Technology Ministry, through the National Council of Scientific and Technological Development (CNPq, from the Portuguese *Conselho Nacional de Desenvolvimento Científico e Tecnológico*) of Brazil. The research team included members of the Micropolitics of Labor and Healthcare

Research Area (Universidade Federal do Rio de Janeiro) and workers of the mental healthcare network of the Dr. Cândido Ferreira Healthcare Service, Campinas, Brazil. The project was approved by the Research Ethics Committee of the Clementino Fraga Filho University Hospital of the Universidade Federal do Rio de Janeiro.

## Important concepts in the construction of the methodology

There are studies in the healthcare field that understand the idea of territory as something physical, rigid and geographical. In truth, individuals, as users of healthcare establishments, generally seek out different relational ties with different possible territories in a very unique manner, taking this construction as subjectivizing. Therefore, the concept of territory is existential and situational, and has several meanings.

Thus, on the one hand, users appropriate for themselves the geographical territory, socially constituted as a reference that has meaning to them. In this way, their neighborhood and everything in it, in terms of institutional infrastructure, are subjective references, as they belong to the field of territorial meaning. On the other hand, that dimension in itself is also cultural and, as such, goes beyond the geographical, in such a way that users build another geography: they try to find other opportunities they consider more adequate located in places other than their own neighborhood or workplace (2,6).

Regarding the field of mental health (7), this second situation is very significant. Users are "nomads" in healthcare networks, in fact having a central role in the production of their own health care (8,9).

This triggers a methodological problem: taking health institutions as the center for the construction of information sources does not allow us to see the care produced in all of its complexity, which runs along existential flows that enable multiple relational processes constructed by users in their ways of moving through life (10).

In this way users of healthcare networks, though closely linked to certain healthcare teams, are not exclusive users, even though territorialization is strong. They consume and produce other

ties. They are “nomads” in the sense that they produce networks of existential connections unforeseen and unknown in the world of healthcare; networks of connections that go beyond the places established by healthcare services.

Therefore, our cartography could not be limited to the construction of therapeutic itineraries. It was necessary for us to walk with the users and discover the production, many times in action, of new networks of connections. Every “healthcare station” would be a source for revealing access and barriers, but they would not be enough on their own (11).

In other words, users in general have “nomadic” behavior through networks of connections of care, as they do not exclusively use health teams to receive care; they produce other and new deterritorialized network-events, resulting from their “nomadic” way of moving through life (8).

Thus, while healthcare stations were important sources initially, it was essential for us to use multiple investigation strategies capable of working with the different regimes of truth that emerge; for instance, those regimes produced during subjectivizing processes created by the micropolitics of impromptu encounters that form part of different ways of moving through life.

Due to the features of the health field itself and how ways of living are produced, it would be necessary to explore the unique nomadism of each user, taking them as a case-guide, in order to learn how new networks of care are constructed. These networks of care can exist outside the healthcare system, and are often constructed by users with the purpose of overcoming barriers to care. On other occasions, these networks outside the healthcare system are constructed out of unforeseen encounters.

This is why we incorporated into the methodological perspective of Merhy and Feuerwerker, which was previously used in other studies (12,13), the methodology used by the historian Ermínia Silva (14) in her study of the social history of circus-theater culture.

In order to deal with the nomadism of circus performers and the circus itself in her investigation, Silva worked with the trajectory of some artists, using them as guides that allowed her to map places, institutions, practices and knowledge. This in turn enabled her to chart networks with

multiple connections, gaining her access to diverse sources that gave her elements to construct the memory of way(s) of living in the circus, in the nomadic movement typical of this social group.

In our mental health study, health teams were the initial sources used to find the cases of “user-guides” that would allow better mapping and analysis, within a rich substitutive network with a wide range of options, of the barriers to and accessibility of mental health care.

As the social production of health is carried out by living labor in action, the construction of knowledge about this labor demands we go beyond a simple subject/object relationship. This feature of living labor in action, which cannot be fully tracked, requires the direct involvement of the researchers themselves in that production to provide certain information, albeit fragmentarily. Furthermore, as it is a process that has narrative implications, it is necessary to work constantly to find other sources of different origins whose multiplicity enables us to analyze, by way of their otherness (5), the process of construction of certain regimes of truth, in the words of Foucault and Deleuze (15,16).

## THE STEPS OF THE INVESTIGATION

One of the first debates was connected to a typical practice in the field of health research which involves analyzing users by taking their diagnosis as a point of reference. The team discussed that by basing ourselves in the diagnosis, we would diverge significantly from our aspirations, as these diagnoses are in many cases produced as a result of considering mental illness as a disease, that is, in a restricted way. The limitations and implications of this perspective, of this regime of truth, have been identified in very provocative and revealing studies, such as those carried out by Foucault on the emergence of madness and its construction as the object of psychiatric medicine (17). Adopting this point of view would mean being subjected to its limitations, because intensive users of services, who require multiple modalities of care, do not necessarily have the most dramatic diagnoses from a medical point of view – other elements establish the complexity

and gravity of their situation. Additionally, all the different diagnoses are condensed into the International Classification of Diseases, within a framework intended to restrict rather than amplify, thus limiting the possibilities of researchers who aim to look at the production of networks of existential connections. Users, with their complex lives and implications, go far beyond what their diagnoses might suggest, even as a point of reference for the production of care. Especially in the case of a study like the one we were intending to carry out.

Therefore, we started out with the definitions produced by the group of Campinas healthcare workers regarding the “very mad,” that is, those who most intensely required services from healthcare teams in the daily production of care. The “very mad” demanded with their actions the greatest capacity for creating interceding logics of encounters, regardless of their diagnosis (2).

We therefore expected to obtain, as study material, ways of producing certain types of attention for madness, placing the access/barrier tension as a part of the daily construction of care and not necessarily as a physical movement from a place outside the health service to another inside it, or from a certain level of care to another, as a line of action in the field of services.

Each collective – teams belonging to the different types of services that make up the mental healthcare network – chose a case. These cases were extensively reconstructed by the collective based on the memories of the teams themselves. In this first instance, the collective produced trajectories in an analyzer flowchart – maps of existential territories – thereby creating a certain cartographic process with each instruction we gave them. This was all done provisionally, for the sake of experimentation; the idea was to build markers and references that would allow us to move through those territories of connections.

The “Branca case” was paradigmatic in the development of the cartographic research design; it was based upon this case that we formulated the notion we would later adopt regarding the construction of “networks of existential connections.” Through this case, we perceived the necessity of combining the “life history” with the “history of the family unit,” the “history of the territory of everyday life,” the “history of the disease,” the

production of the “map of what is established in the connections with healthcare services,” and the necessity of highlighting in this mapping process the part belonging to the field of mental healthcare services.

Furthermore, we observed that there were many “Branca” within this study, defined situationally according to the connections that were produced. We understood the necessity of following the narratives that could shed light upon these multiple productions, comparing them, putting them into conversation with one another and trying to interpret them. We also understood that we should explore all the possibilities of narrative construction of the different regimes of truth operating in our production, in the “texts” we found in the exploration and in the study of the oral and recorded sources that each “case” opened up to us.

We came to understand clearly that each “life history” is actually a multiplicity of stories and narrating them using different sources created planes of transversal connections that acted one on top of the other, giving a multifaceted image to the production of life.

From this perspective, there was never a case, but rather many connections and lines of meaning that were produced as the encounters were exposed, encounters not only “personified” but also representing other kinds of events of very different natures. For example, an encounter with a work of art may trigger new lines in the forces of subjectivation, redefining our existential territories and new connections with the multiple ways of living.

However, it was challenging to observe these different guide-cases given the diversity of the encounters exposed, encounters in which connections and power relations were constantly reformulated in terms of the production of access and barriers. We came to understand this production as the enabling or inhibition of networks of existential connections.

It should be highlighted that in this construction we used in an exploratory way the concept-tool “nomadic user-guide,” which we developed throughout this project, taking as a reference the studies conducted by Merhy and Chakkour (18), Merhy and Franco (19) (on analyzer tools and analytic maps), and Silva’s works (14). In this process we could observe that the

production of memory as a tool for constructing the cases was only one of many possible methods, requiring a clearer problematization of the rules of enunciation behind these narrative choices, inscribed within the memories produced.

Regarding this problematization, we took as an example the necessity of understanding how the rules enunciation of classic psychiatry impose certain signifying ideas and constructions regarding madness as a disease. We also explored the effects these impositions produce in the fields of the forces of the subjectivation processes of social collectives. For this reason we sought to create our own enunciations and think about their rules, so that they could work as concept-tools not only serving as representations, but also producing meaning in our own perceptions and affects.

Below we present some elements of the construction of these concept-tools, in an attempt to show the meaning they had for us in different moments of the construction of the “cases” studied.

### Networks of existential connections

Something we noticed while studying the “Branca case,” and later confirmed with the other “user-guides,” was that we could generate maps of her ways of existence that were non-linear and non-hierarchical within the design of her ways of life. Many times, these ways of existence were triggered at the same physical time, which did not mean the same logical time, obliging us to construct an image based in a unique field of meaning, to which certain relations and encounters with others – people, services, facilities, events, etc. – pertained, allowing us to speak about specific existential connections. Various types of networks appeared at the same time, which produced meaning in and of themselves and also spilled into others without asking permission and without maintaining relations of subordination or determination among them.

### Life trajectories

As we worked with *nomadic user-guides*, we were carried along their “n-1” trajectories (multiplicity formula), trying to transit and draw these

trajectories, generating a visual record. We realized that we could provide a line of signification for some trajectories, for example: a trajectory as a mentally ill person, as a student of particular course, as a type of worker, as a member of a certain group. We did not try to define whether or not they were related, whether or not they had lines of determination. That was not our focus. We were interested in looking at the “n-1” ways of producing paths, following them in the networks where they were effectively inserted and created, producing results that were sometimes unpredictable and which affected the field of health relationships, but could not be considered part of the purview of health care or protocolized as technological resources for healthcare actions. What was meaningful for some user-guides was for others a reason to distance themselves.

### Life history

It is not possible to find linearity in this construction, and there is not just one way to include it in the account of this study. Therefore, we translated this history into many histories.

#### *History of the family unit*

We observed that one of the histories producing effects in the field of care itself was related to the construction of trajectories in the networks of existential connections in which a family unit could be recognized. For instance, the way in which certain behaviors of a young person came to be considered “bizarre,” eventually leading to their internment in a mental hospital, with grave consequences for other aspects of the production of their existence. Even though we did not observe obligatory lines of determination, we did observe the production of effects in other territories.

Joaquim and Magda, two of the user-guides studied, provided us many elements with which to understand these processes. As their situations were framed within the narratives of their relatives, we could observe the construction – also imaginary – that they were mad and, as such, they “deserved” a certain kind of care and monitoring. The place occupied by the history of the family unit, taking the *nomadic user-guide* as an ordering

axis, was very enriching for our material, though it required that we also understand what these users brought with them as a result of their encounters in a territory not identified as family-based: the territory of everyday life.

**History of the territory of everyday life**

We highlight here all the possible connections, completely unpredictable and of different types, which allowed us to recover the user-guides’ histories with other people outside of their families. For example, when Joaquim was a child he lived in a rural area. He had multiple ties with others who did not belong to his family unit and other activities and encounters not defined *a priori*. It is not easy to include some of these histories in the construction of a narrative, as it is almost impossible to utilize sources from the past, but fortunately in some cases there were vestiges of that production which we were able to access. This territory of everyday life has profound effects on the field of disease and in life in general.

**History of the disease**

These histories provided the richest narrative material among our cases, as they represented the core of what is produced in the way of living of the users according to their trajectories constructed as “mad” people. Here their narratives are deeply marked by the rules of enunciation that appear in the discursive construction of the different sources originating institutionally in healthcare services. Frequently, the user is reduced to a diagnosis or to a certain stereotype constructed in the health services by the workers and the characteristics of the institution. Therefore, the “Joaquim” of the mental hospital is different from the “Joaquim” of the substitutive services.

**Map of what is established in the connections with healthcare services**

This mapping was intended to give visibility to the different types of services to which the cases were connected and that have established them as users. It is an approach to working with the idea of therapeutic itineraries, but as such a map

is demarcated by the structure, it was necessary to invade it with other narratives including those which update networks of care, provided by effective caregivers (who are diverse, from different places, and vary over time), in order to bring into focus the micropolitics of living labor in action, disordering the narrative of that which is established.

**Networks of care in action: user-guides’ nomadic forms of moving through their multiple ways of living**

This was a place key to moving forward in the cartographic logic that was being produced, as well as in the diverse trajectories and connections that the territory of care had made possible. Its visibility was evidenced inasmuch as, through narratives and records, we could explore the tension between the micropolitics of doing in action— constructing the caregiver-care relationship — and the world of dead labor, established in the rules and action protocols of healthcare organizations and institutions.

For example, in different moments Magda reencountered herself in the connections she was able to produce and by which she was produced in the universe of encounters through which she passed at a psychosocial care center, with other users as well as with her team of reference; the same occurred in her experience living at a boarding house and interacting with its owner. Using the information sources to construct this mapping process proved to be fundamental.

**AN INTENTIONAL CONSTRUCT OF THE STUDY: THE ALGORITHM “MEASURING” ACCESS AND BARRIERS**

Seeking out indicators of access and barriers is a classic effort within the health field, which is generally limited to the construction of quantitative indicators, for example:

- Number of expectant mothers with prenatal care in the first trimester of pregnancy.
- Number of children under the age of one with complete polio vaccination.
- Number of schizophrenic users that were able to consult a psychosocial healthcare center in their territory.

- Number of cataract carriers operated in a certain population and territory.
- Number of patients in the mental care network hospitalized in asylums inside or outside of their region.
- Number of patients with mental illness seen by emergency and urgent care services that were enrolled in the psychosocial healthcare center in their territory.
- If the answer is negative, then it is necessary to acknowledge that the access to that care is producing barriers to a better quality of life.

Many indicators have been created to evaluate healthcare services or networks. All of them are relevant, but all of them bear the same mark: they understand access or barriers as almost material and physical phenomena of someone from "outside" who is either able or unable to enter the service and obtain care, be it a specific service like a psychosocial healthcare center, a modality of care, hospitalization or a therapeutic workshop.

However these indicators do not usually reveal, as this study shows, other fundamental dimensions, given that many times "entering" a certain network of care could be the best way to encounter a barrier, from the point of view of the construction of a care that produces "more life" in an individual's ways of existing.

We can see here a complex challenge that we want to express in this article by showing how we intend to face the problem of constructing indicators of processes that can only be comprehended qualitatively. Therefore, we propose the possibility of constructing an "algorithm" starting from a very simple base:

- Is the person being cared for amplifying or diminishing his/her networks of existential connections?
- If the answer is affirmative, then more life is being produced.

In other words, depending on the case and the modality, the care that was accessible and established can work as a barrier to the production of life. Therefore, this algorithm may tell us something about the object of our investigation. Or more precisely, we believe it indicates qualitatively, without numbers, but with expressive force, the production of ways of living that produce more life in a person's existential field.

That is why we insist that "*access and barriers must be observed according to the logic of the production/inhibition of existential connections,*" which may indicate to us an innovative product of this study.

We obtained this image from the poverty, or more accurately, the misery of options produced by hospitalization in closed institutions. In asylum-based care, greater capacity for producing death than for producing networks of life connections is generated. Therefore, barriers to care are produced.

Likewise, in unenclosed institutions such as the psychosocial healthcare centers or similar institutions, situations can be identified in which clinical practices can act as a barrier or just the opposite.

Observing all processes of care established in institutions or in encounters in general as generators of therapeutic effects opens up for us, from the point of view of the production of identities and contractualization, a new universe in the production of knowledge regarding the object of this study.

We imagine that this construction can become a new type of indicator to be used in the evaluation of networks of care in general and not exclusively in the field of mental health.

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