

Narratives on health: reflections on care for people with disabilities and genetic disease within the Brazilian National Health System

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The factors that influence effective healthcare for people with disabilities and genetic diseases within SUS include the presence of stigma, relationships marked by biomedical power and institutional violence. This article aimed to discuss the issues that run through this care, guided by narratives on this author's experiences of caring for children and families. This text was written in essay format and discusses the issues surrounding healthcare and benefits, within the context of practices driven by biomedicine and biopower. The narratives reveal the transforming capacity of affection and additional potential of meetings, marked by circuits of benefits and guided by construction of interpersonal relationships between professionals and service users that promote new spaces and forms of healthcare.

Keywords: Comprehensive Health Care. Narrative. Medical genetics. Disabled persons.

Introduction

Brazil's National Health Policy for People with Disabilities¹ established guidelines concerning the provision of comprehensive healthcare for people with disabilities in the *Sistema Único de Saúde* (SUS – Brazil's National Healthcare System). In 2014, the Ministry of Health published the National Policy for Rare Diseases², which defines and organizes the provision of healthcare for people with rare diseases – those that affect up to 1.3 people among 2,000 individuals. The organization of this type of care, in its first axis, is composed of rare diseases of genetic origin, including congenital anomalies, late onset anomalies, intellectual disability and inborn errors of metabolism².

Despite the guidelines that were already defined by such policies, the provision of healthcare for people with disabilities or genetic diseases in primary care services and specialized outpatient clinics raises some questions about the healthcare that is provided for this public.

This article aims to discuss some issues that pervade the way in which we establish the provision of healthcare for people with disabilities and genetic diseases. We present three cases that were constructed based on the first author's experience of groups that support families of people with disabilities and genetic diseases. These families participate in activities carried out in the public health network. With these cases, we aim to create an identification with the readers' experience and to facilitate and contextualize the conceptual discussion.

The cases are presented in the format of narratives, which guided the construction of the present essay. The narratives enabled the author to perform the synthesis of individual experiences with the social and medical context, in order to

translate her empathy with the narrated stories and to amplify the reflection on the families' reports.

Narrating is one of the ways of bringing the past to the present and enabling new interpretations of what was lived. This linguistic form presupposes the existence of a listener and of the person who tells his/her story, with their worldviews³. The narrative enables the listener to reinterpret the story in his/her own way. In addition, it enables the dialogic integration among subjects, contexts and ideologies⁴. For example, it fosters awareness-raising, the construction of meanings to the situations that were lived, the expression of suffering, and the establishment of spaces for dynamic and interactive encounters and exchanges. Like a kaleidoscope, narratives allow the individual listening of people's stories and reflect the contexts of their production, social representations about the theme, official discourses and the diversity of meanings present in the report.

The theme of health narratives has been discussed by many authors in the perspective of their use as an instrument that potentializes and enriches clinical practice. As a response to the transformations in medical practice that have been triggered by Evidence-Based Medicine, the proposal of Narrative-Based Medicine (NBM) emerges in the 1990s and discusses, based on an interpretive paradigm, the importance of the patient's experience of getting sick and the clinical encounter for the establishment of adequate healthcare⁴.

The use of narratives in the present essay recognizes and incorporates the ideas proposed by NBM. However, it intends to add to this discussion some aspects that influence the provision of healthcare for people with disabilities or genetic diseases, such as the issue of stigma, biopower, and institutional violence. In addition, it proposes that the establishment of circuits of gift in human relations in the area of health can modify the ways in which we provide care.

According to Deleuze⁵, writing is a health task and the writer is the doctor of him/herself and of the world. The character of fable that is produced in literature is a source of transformation, of future events, of life potencies. The challenge placed in

this text regards exercising the possibility of discussing the healthcare that is provided for people with disabilities or genetic diseases based on their narratives and on their families' narratives. This experience report aims to analyze how large narratives, like biomedicine, pervade singular stories in their contexts of formation and reproduction, and also people's experiences and the development of the care that is proposed in the scope of the organization of policies, services and teams.

Telling stories to tell another story about biomedicine and biopower

The technical–scientific advances have generated an increase in the survival of children and adolescents with severe and chronic diseases caused by preterm birth, genetic diseases or congenital malformations. Thus, we have been facing many issues that affect our work as health professionals.

The first one is the stigma. According to Goffman⁶, a stigma is a sign or mark that makes an extraordinary characteristic in one individual become visible to everybody else. It separates this individual from the others and is understood as a derogatory sign. However, it is not the mark in itself that constitutes the stigma, but the relationship that is constructed between this mark in an individual and other people. This allows one mark to be seen in a distinct way in different situations and relationships, which enables us to understand the diverse reactions of professionals in each situation.

The stigma can be seen in a case like Luis's story.

Luis was a boy who barely moved because he had cerebral palsy. His eyes were bright but he had difficulties in fixing them on some point. His little arms and legs were rigid and he was very thin. The mother took him to an emergency service because he was coughing and gasping for air, but the doctor who received her on that Sunday night told her that there was nothing she could do, as they only assisted emergencies and that was a specialized case.... In fact, hadn't she been told that these children couldn't be raised? It would be better to clarify this at that moment, because if the boy survived, it would be like that, in a wretched way and

with no quality of life. When she heard that, those mother's eyes filled with tears. Hadn't she gone there precisely to save her son, to give him air and treat that cough? She swallowed hard, wiped her tears, looked into her son's eyes, the mirrors of his soul, and she knew what to do. She pretended not to have heard all those horrible prognostics and insisted with the doctor on assisting the boy.

Patients like Luis arrive at the healthcare unit already marked by this stigma, which is visible due to his different appearance and behavior, physical abnormalities and the presence of life support equipment or technologies, such as gastrostomies and tracheostomies. This mark, which is carried throughout life, is immediately recognized by the professionals who, sometimes, do not feel "able" or "prepared" to deal with these differences and with the living conditions, they produce. Thus, the presence of the physical stigma was sufficient to make the child and his mother be considered "inappropriate" to be assisted at that service. The doctor even warned the mother that that condition would lead to death.

The stigma is related to values and to a discourse constructed within the biocentered paradigm. On the one hand, technical-scientific development creates new living conditions and new forms of living; on the other hand, the biologicist and mechanistic view excludes aspects of experience, affects and meaning construction when it deals with people in these conditions of existence and of interpersonal relationship.

According to Foucault⁷, power is a social practice that is historically constructed. The power strategies that are employed in the current society are grounded in the biological scope. From this scope, strategies to control the capitalist society in which we live are exercised through a network of devices to which all of us are exposed⁷. Furthermore, power is not constituted only by repressive devices; it also produces individualities and discourses. The world is constituted in spaces, like the family and the healthcare unit, among others, of a social body that is unceasingly pervaded and regulated by a continuous form of power that is exercised in network and circulates among individuals and groups, in a relationship of forces, like a continuous war between two poles⁷.

In the case of relationships in the field of health, biomedical power is established through technical knowledge and through the transformation of the other into an object of medical actions and of encounters based on the exercise of disciplinary power. Medicine is one of the areas in which a disciplinary and regulating power has been best established, in which the exchange between disciplinary mechanisms and the right to make decisions is clearly observable⁷.

Following this line of thought, biopolitics intends to define which mechanisms, interventions and definitions are more adequate and desirable in relation to issues regarding the vitality and morbidity of populations, in order to reach the best results. These concepts are a way of explaining why, in current days, professionals feel legitimated by biomedical knowledge, by the disciplinary power of medicine, and families and patients submit to unilateral decisions to find some kind of access to the health treatment. This scenario, associated with the scarcity of resources in the area of health, can generate much suffering to all the individuals involved, including health professionals, who need to make decisions about the care and the treatments that will be offered.

The relations between determinism and probability, legitimated by scientific knowledge, show what Castiel⁸ has called epidemiopower, which intends to achieve health and life in populations. Nowadays, it is epidemiological knowledge that determines what we will defend as healthy behaviors and the forms that we use to promote the health of the populations we assist⁸. In this perspective, the negative reaction of the health professional who receives a patient who has survived serious neonatal complications or a genetic disease – a patient who lies outside what is expected by health statistics – is not unreasonable. When we think about this, we realize that the ideas about the future of patients with severe chronic diseases, who many times depend on technology to survive, are directly affected by the way in which power relations are socially established and by the knowledge that is legitimated by biopower/epidemiopower. In addition, medicine's perspective of success is constructed through the successful diagnosis and treatment of injuries. Thus, when

the injuries are not susceptible of intervention, the professional feels lost in his/her professional project.

The control exercised by/over us by biopower generates a sensation of “pseudo-safety” that allows us to, for example, speculate about which lives are valid and possible. This situation is revealed in Maria’s story.

Maria was a baby with hydranencephaly who was always seen as a lost case. She was still in the uterus and the mother used to hear: this baby will not survive the first hours, the first days. After nine months, Maria is born crying loudly and does not need assisted ventilation. Some days later, she goes home. The mother observes her little daughter and tells the doctor in the first consultation: look, she is my baby, she cries and sucks my breast, she poops and pees, she is like all the other newborn babies. The doctor examines the tomography and confirms the existence of hydranencephaly. She has to decide, looking at the tomography and the child, what to do: should she send the child home or should she stimulate it in physiotherapy? Her thoughts concentrated on the scientific knowledge about the brain, about what to do with a baby with no brain and its mother, about the possibilities of improvement, about risk and benefit. Against all the biomedical reasons, she observes the mother and shelters her at that healthcare service. The mother had reinvented that baby... The months went by and in each consultation, the mother told the same story: look, she is my baby, she cries and sucks my breast, she poops and pees, she is like all the other babies... It never had any neuromotor development... The baby died assisted by the service when she was 1 year and 2 months old...

The narratives also reveal records of power perpetuation and the institutional violence to which users of services are submitted. Pierre Bourdieu⁹ calls symbolic violence the type of violence that is perpetrated by individuals who are in a position of power, so that the real intentions of maintaining the established power are masked. Thus, the situations that occur are legitimated, both to those who dominate and to those who are dominated. In many cases, the violence that occurs in institutions have this characteristic.

This type of violence is so naturalized and legitimated in discourses and acts that it may not be recognized as such by those who are submitted to it. In the cases narrated here, despite the situations of suffering and violence, the families try to maintain the possibilities of treatment by remaining silent and avoiding a direct confrontation with the professionals. The instituted biomedical power disciplines the families' behavior. Non-confrontation reveals the naturalization and banalization of such situations, which are institutionalized and start to be seen as things' natural way of being. Fleury and collaborators¹⁰ approach the naturalization and legitimation of institutional violence and argue that the most common way in which users of health services in Brazil react to these situations is naturalization, accompanied by a search for individual solutions to the problem, which favors the maintenance of violence situations in the services. In addition, denial, submission and individual or collective resistance can occur. The invisibility of discriminatory actions, the services' lack of structure, which strengthens the professionals' power of choice regarding who to assist and how, and the presence of stigmas / stigmatizing situations in professionals and users were cited as possible causes for denying the population's right to health.

According to Gomes, Nations and Luz¹¹, men and women who were hospitalized in the Brazilian Northeast region reported, in 83% of the cases, that there was humiliation and negligence towards their health and only 16% mentioned that there were situations to protect their health. The main strategies that the patients used to deal with or resist the violence that occurred were personal characteristics, religious faith, creativity and solidarity. The authors found reports of suffering, power abuse, discrimination and demoralization. Stigmatizing situations were highlighted by the patients' reports. We observed that similar situations occurred in the stories narrated here. Families must face not only the stigma of having a child with a disability or a congenital malformation, but the exposition to situations in which institutional violence is present.

Enlarging and recognizing new forms of care

The construction of interpersonal spaces for the exchange between professionals and users of healthcare services can foster the resignification and reevaluation of care.

One possibility is the movement of illuminating the situations experienced in the daily routine of healthcare units. The point of departure of this process is to recognize users and their relatives/supporting network as subjects and protagonists in the relationship with services and teams.

To achieve this purpose, giving visibility and analyzing the narratives constructed among professionals and/or among them and the families can be a tool of resistance and transformation, making the exegesis of new possible meanings to the violence situations that were experienced.

In the narrative about Benjamin and his family that is presented below, we have a child receiving longitudinal care, assisted by a team that balanced the use of technologies and the performance of interventions with over-time monitoring, focusing on reducing his suffering.

We paid a visit to Benjamin at his home. He couldn't see, couldn't walk, couldn't speak and couldn't eat. He had a feeding tube in his stomach. The team of the healthcare unit was always present and the family felt sheltered and assisted. In spite of the gravity of the case and of the rarity of the degenerative disease, he lived well in that house and in that neighborhood. When we arrived there, he was on the sofa and there was a football match on the television. The boy supported Vasco, according to the mother. What we felt there was that it seemed to be a miracle. Despite the countless problems, it was as if that family treated us. We performed the necessary procedures, oriented the treatment and everything. We supported that mother's inventions, like the idea of cleaning the feeding tube with a small brush that was originally created for the Papanicolaou's test. Despite all the difficulties, we used to leave that house feeling light, sheltered and warmed by that family's and that boy's energy. The mother said that, in every place that she went, she heard that painful question: was that life worth? Did the little boy live or vegetate? Then she smiled, despite the pain, and remembered her objective there: quality of life and reducing his suffering. And she moved on.

Benjamin's story highlights some issues. The first one is that we should visualize the care practices as a fusion of horizons: patients' and professionals' expectations and desires¹². According to Ayres, to achieve this, it must be possible to take care of the patient in a comprehensive way, through knowledge of his/her life projects, so that a longitudinal relationship can be established, with a genuine concern about the practical success that needs to be achieved. This, and not scientific knowledge, gives meaning to care practices. In the case of Benjamin's family, this fusion of horizons is revealed in the care that is shared between the mother and the team, in the objective of reducing the boy's suffering.

The second issue regards the constriction of the ways of conducting life and the view according to which pathologies reduce the limits between which life is possible, a reduction that is expressed through suffering¹³. Therefore, a comprehensive care practice regards the capacity for enlarging this constriction, or contributing to prevent it from worsening. This means responding not only to suffering, but also to the early identification of other issues that may affect the way of conducting life, enabling health promotion and prevention actions¹⁴. Thus, changes in care practices are promoted in order to amplify horizons, either by enlarging the constriction produced by the disease, or by life resignification processes, even in the presence of constrictions.

The third issue is related to the dimension defined as the happiness project. This concept, proposed by Ayres¹⁵, questions the existential meaning of the individual's life. Thus, although the results of care practices can be classified as having a technical success, sometimes they do not achieve a practical success, which can encompass biological and non-biological questions.

The recognition of health needs must be the teams' target. To achieve this, listening to users must be a priority, and this requires learning about their life histories. According to Cecílio¹⁶, health needs can be categorized in different dimensions: adequate living conditions; free access to technologies; effective bonds with the team; the patient's capacity to make his/her own choices in his/her way of

life. So that we can have answers in the comprehensive care provided for these needs, Ceccim and Ferla¹⁷ propose that the most adequate design is making the teams be in charge of the provided care, as well as valuing and using local resources, which are singular.

The utilization of practical experiences in the care construction process can be an instrument to help teams. The team's acceptance of an adaptation proposed by Benjamin's mother for a technical procedure is an example of this utilization. The appropriation of these concepts by the teams and the search for existential meaning in therapeutic attitudes can potentialize healthcare as a tool that aids the reinvention of life. The reason is that, based on the contact with the other, either in a personal relationship or in the professional-user relationship, it is possible to establish a dialogic and rich experience that strengthens the potentials of the people and families involved and promotes the development and amplification of resilience.

Person-centered medicine, a concept proposed by Stewart and collaborators (1995), cited by Ribeiro and Amaral¹⁸, is a way of acting of the health professional that has two main pillars: providing care for the patient while identifying how he/she understands and experiences his/her disease, and identifying common objectives of professionals and patients regarding what must be done, sharing decisions and responsibilities. This concept has a lot in common with the ideas of happiness project and fusion of horizons^{12, 15}, and also with the identification of patient's needs^{16, 17}. The healthcare teams' action in providing care for people with disabilities, congenital malformations and genetic diseases must take these issues into account, as the narrative about Benjamin and his family showed.

The concept of gift has come from the social sciences and is based on the triad composed of giving, receiving and reciprocating, which, according to Marcel Mauss, quoted by Falleiros¹⁹, form a complete circle. Apparently, the gift has a voluntary and free character but, at the same time, it is obligatory and committed; in fact, it is a transaction. The goods that circulate guided by the gift paradigm are secondary in relation to the bonds and relationships that are created. Thus, the exchanges that occur in this circle start to have meaning. The gift circle is continuously pervaded by

power relations, which sometimes strengthen, sometimes weaken the bonds among people.

The encounter as a gift space strengthens the power of social relations and, in this space, the positions of donor and done are neither fixed nor hierarchized²⁰. This type of bond pervades the relationships between health professional and user, enabling the power relations to alternate and to be distributed within each one of the groups.

In the same way that power relations are producers of new possibilities, so are the relationships that involve giving, receiving and reciprocating. That is why it is important to highlight, through narratives, the impossibilities, the experienced violence, the pain and the suffering that have been caused. Thus, the focus that is placed on the experience enables to recognize that other practices may be possible and necessary.

The establishment of gift circuits in human relations in the field of health, allowing the construction of bonds and encounters characterized by solidarity, as Benjamin's story showed us, are forms to face or resist stigmatizing or institutional violence situations. This is essential for humanized healthcare.

Furthermore, it is important to mention the fact that healthcare is, in the majority of cases, characterized by the production of procedures, rather than being perceived as an encounter space. This hinders the establishment of relationships guided by the concept of gift²⁰. The structure of the institutions and of the ways of providing healthcare, which is, many times, rigid and hierarchized, can reduce the power of encounters in the area of health and of the gift circuits that are established²⁰.

The possibility of giving, receiving and reciprocating enables to see, in the other person, a subject, and to confirm one's own condition of subject²⁰. It is the acceptance of the condition of subject by the parties involved that allows the establishment of dialog and the possibility of true encounters. There is no dialog when relationships are configured in a way that the subject is not seen as such and is treated like an object, which strengthens the power relations and places the subjects in a position of inequality⁷.

The break of the gift circuit and the institution of unequal relations pervaded by a regulating and disciplinary power does not occur without resistances. These are offered by any of the participants in the subject-object relationship, in which it is not possible to establish intersubjectivity, dialog, bonding and the responsibility for the other individual.

In Maria's and Benjamin's stories, we see that the professionals recognize the subjects (patients and families), and true encounters are established in spite of the gravity of the patients' clinical conditions. There is the recognition of the patients' and families' suffering, as well as the proposal of strategies that aim to mitigate or, at least, not aggravate the suffering, and to provide support and solidarity. It is health reinvented. True circuits of exchange and gift are instituted and the people involved respect alterity.

Health practices are established through relationships characterized by intersubjectivity and dialog. It is necessary to establish a dialog among teams, communities and families in order to define and recognize individual health perspectives, available resources, necessary adaptations and, last but not least, who will act in a transforming way to meet this expectation.

The construction of a common language between professionals and patients may enable exchanges and gifts. One way of making effective care happen in practice is to be open to listen to narratives, to understand contexts, to integrate practical knowledge and technical knowledge, and to recognize new meanings about chronic illness and disability. Within the team, opening spaces for the discussion of cases, for the collective construction of therapeutic projects and for narratives about diseases and care that the professionals construct can be one more tool to be used.

Care practices provided for people with disability and genetic diseases in Primary Care

The advantage of Primary Care in the development of resilience in individuals and families is the possibility of a very close relationship, which allows the

identification of risks and intervention possibilities. This relationship must be based on a type of healthcare that respects the dialogic dimension of the encounter, in which the team focuses on the presence of the other and allows the non-technical horizon to enrich the technical one. The characteristics of this team are being receptive and creating a bond with the families it assists.

The health needs of people with disabilities and genetic diseases are determined or aggravated by extremely complex social processes²¹. This fact strengthens the importance of the construction of healthcare practices for this group taking into account the living conditions and subjective issues that are involved. The social and economic impacts, among others, are huge and the presence of a disability contributes to strengthen situations of poverty and social exclusion in the families²². These dimensions must be considered so that it is possible to promote therapeutic practices that aim to achieve practical success.

The health practices pertaining to each specific situation do not exist per se. They must be constructed taking into account the complexity of the situations that will be faced, using technical and non-technical tools. It is suggested that recognizing and valuing the creativity processes of patients, families and teams, as well as their experience, allows the production of successful results.

We would like to highlight the importance of focusing on the dialogic dimension of the encounter among professionals, families and communities, like in Benjamin's story. Likewise, home visits can help health professionals to identify with disabled users and their problems, and to feel co-responsible for possible changes and for the construction of happiness projects to the families. Some innovative and heterodox proposals are included here, based on practical knowledge. In this sense, the professionals' creativity processes are triggered, potentializing Primary Care as part of rehabilitation.

As final remarks, we would like to list some possibilities of health intervention that can potentialize the health of people with disability and genetic diseases: the recognition of people's life history, the exchange of roles, and the utilization of local knowledge and health practices. Interventions must be performed in the perspective of

enlarging horizons, reducing suffering, and amplifying the possibilities of emancipation and autonomy. Thus, health practices must not be centered exclusively on scientific knowledge, which remains valid, but on the needs of the individual who suffers. This must be the meaning that motivates health workers. The rationality must be shifted from the disease to life, from the results of interventions and technical successes to practical successes and the re-signification of life.

Some of the issues that were presented here are the structural and symbolic violence suffered by users and the violence suffered by professionals, which can be considered one of the faces or causes of the institutional violence that remains in the healthcare system and which possibly contribute to dehumanize the subjects involved and strengthen the situations of violence.

But how can one let oneself be affected by relationships in health, face violence and modify affects?

According to Spinoza's *Ethics*²³, affections are the forms in which reality is self-affected or affected in encounters with other ways of being. Thus, the modulation or transformation of reality or substance is processed. Affects, in turn, are feelings, which represent the gain or the loss of power and the perception of this transforming flow, like happiness and sadness^{23, 24}.

Borrowing Spinoza's idea of affection, we understand that the suffering and violence that are experienced in encounters among people are ways of affecting reality that, per se, generate affects. However, although they apparently are situations in which there is a reduction in power, and this may generate a decrease in the flow of life, we believe that there are other ways of facing them.

We propose here that one of these ways is the construction of stories, of narratives about experiences, of discussions on what was told. Thus, we propose reviving what was lived, opening spaces for discussion and for the construction of lines of escape towards what is possible.

To narrate means telling a story and making visible, to the others and to oneself, the meanings of the experienced facts. It is an act that enables inventing or reinventing new forms of the experience. It strengthens the capacity for resilience of

the person who narrates and of the person who listens to the story. The inventive capacity of language is a way of highlighting experiences and enabling the identification of new metaphors for what was lived, as suggested by Richard Rorty²⁵.

To narrate, here, is an act of resilience and of resistance against the structural violence to which all of us are exposed.

Therefore, we propose that it is possible to transform affects, potentialize health encounters and create new possibility spaces. Perhaps, spaces pervaded by gift circuits, in which, more than giving, receiving and reciprocating, a true encounter happens. Potencies of the new that allow, through the visibility of similarities and differences among subjects, that the human dimension is strengthened, and that the true humanization in the field of health is processed.

Collaborators

The authors worked together in all the stages of the production of the manuscript.

References

1. Ministério da Saúde. Secretaria de Assistência à Saúde. Portaria nº 793, de 24 de abril de 2012. Institui a Rede de Cuidados à Pessoa com Deficiência no âmbito do Sistema Único de Saúde. Brasília (DF): Ministério da Saúde; 2012.
2. Portaria GM/MS nº199, de 30 de janeiro de 2014. Institui a Política Nacional de Atenção Integral às Pessoas com Doenças Raras. Diário Oficial da União. 31 Jan 2014. Seção 1.
3. Grossman E, Cardoso MHCA. As narrativas em medicina: contribuições à prática clínica e ao ensino médico. Rev Bras Educ Med. 2006; 30(1):6–14.
4. Favoreto CAO, Camargo Jr KR. A narrativa como ferramenta para o desenvolvimento da prática clínica. Interface (Botucatu). 2011; 15(37):473–83.
5. Deleuze G. Crítica e clínica. São Paulo: Editora 34; 1997.
6. Goffman E. Estigma: notas sobre a manipulação da identidade deteriorada. 4a ed. Rio de Janeiro: Editora Livros Técnicos e Científicos; 2012.
7. Foucault M. Microfísica do poder. 19a ed. Rio de Janeiro: Graal; 2004.
8. Castiel LD. Saúde, longevidade e genética: um olhar biopolítico. In: Santos RV, Gibbon S, Beltrão J, organizadores. Identidades emergentes, genética e saúde – perspectivas antropológicas. Rio de Janeiro: Fiocruz; 2012. p. 71–91.

9. Bourdieu P. O poder simbólico. Fernando Tomaz, tradutor. 16a ed. Rio de Janeiro: Bertrand Brasil; 2012.
10. Fleury S, Bicudo V, Rangel G. Reacciones a la violencia institucional: estrategias de los pacientes frente al contra derecho a la salud en Brasil .Salud Colect. 2013; 9(1):11–25.
11. Gomes AMA, Nations MK, Luz MT. Pisada como pano de chão: experiência de violência hospitalar no Nordeste Brasileiro. Saude Soc. 2008; 17(1):61–72.
12. Ayres JRCM. Sujeito, intersubjetividade e práticas de saúde. Cienc Saude Colet. 2001; 6(1):63–72.
13. Canguilhem G. O normal e o patológico. 4a ed. Rio de Janeiro: Forense Universitária; 1995.
14. Mattos RA. Os sentidos da Integralidade: algumas reflexões acerca de valores que merecem ser defendidos. In: Pinheiro R, Mattos RA, organizadores. Os sentidos da integralidade na atenção e no cuidado à saúde. Rio de Janeiro: UERJ, IMS, Abrasco; 2001. p. 39–64.
15. Ayres JRCM. Cuidado e reconstrução das práticas de saúde. Interface (Botucatu). 2004; 8(14):73–92.
16. Cecílio LCO. As necessidades de saúde como conceito estruturante na luta pela integralidade e equidade na Atenção em Saúde. In: Pinheiro R, Mattos RA, organizadores. Construção da integralidade. Rio de Janeiro: IMS, UERJ, Abrasco; 2003. p. 113–26.
17. Ceccim RB, Ferla AA. Residência Integrada em Saúde. In: Pinheiro R, Mattos RA, organizadores. Construção da integralidade. Rio de Janeiro: IMS, UERJ, Abrasco; 2003. p. 211–26.
18. Ribeiro MMF, Amaral CFS. Medicina centrada no paciente e ensino médico: a importância do cuidado com a pessoa e o poder médico. Rev Bras Educ Med. 2008; 32(1):90–7.
19. Falleiros GLJ. A dádiva e o círculo: um ensaio sobre a reciprocidade a Uwe xavante [dissertação]. São Paulo (SP): Universidade de São Paulo; 2005.
20. Guizardi FL, Pinheiro R. Quando dádiva se transforma em saúde: algumas questões sobre a integralidade e o cuidado nas relações entre sociedade e estado. In: Pinheiro R, Mattos RA, organizadores. Cuidado: as fronteiras da integralidade. 3a ed. Rio de Janeiro: IMS, UERJ, Cepesc, Abrasco; 2006. p. 37–56.
21. Othero MB, Dalmaso ASW. Pessoas com deficiência na atenção primária: discurso e prática de profissionais em um centro de saúde–escola. Interface (Botucatu). 2009; 13(28):177–88.
22. França ISX, Pagliuca LMF. Utilitarismo, pobreza e desenvolvimento dos portadores de deficiência. Rev Latino–Am Enferm. 2007; 15(n. esp):857–63.
23. Spinoza B. Ética. Tomaz Tadeu, tradutor. Belo Horizonte: Autêntica; 2007.
24. Passos E, Benevides B. Passagens da clínica. In: Maciel A, Kupermann D, Tedesco S, organizadores. Polifonias: clínica, política e criação. Rio de Janeiro: Contracapa. 2006. p. 89–100.

25. Rorty R. Contingência, ironia e solidariedade. São Paulo: Martins Fontes; 2007.

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