

Trajectories and moral experiences of rare and chronic illness in biographies: a theoretical essay

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Abstract *Our subject is a dialogue with six literary works, understood in the publishing market as biographies that consider first and second person narratives on the relationship with situations of chronic, rare or complex disease. As a theoretical essay, we try to build an argument: these biographies are public forms of people's construction and presentation; they represent the possibility of assigning a place of visibility to moral experiences, of great public appeal, but which must be recognized in health care and training as political tools for reflection on practices. Thus, they become testimonies, providing less personal life histories and more biographical paths, with an interactionist dialogue among meanings, places, people, positions, stigma, right violations and discrimination.*
Key words *Rare diseases, Moral experience, Testimonies, Biographies, Paths*

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Introduction

Some universes of research – purposely universes, in the definition of social and human sciences, to think about interactions between people, places, and times, but which also, in a poetic license, embrace a metaphor that evokes constellations, stars, and planets – do not allow us to just an external perspective. Inspired by Laplantine¹ and Velho², the anthropological task of looking triggers the inside and outside, in a clinging or contrasted way, in the relationship between finding it strange – because it is outside – and becoming familiar – because one wants to look inside. This attitude implies several movements, such as a dance, where partners develop movements in a dynamic of retrieving encounters, overcoming accidents, mismatches.

Rare, complex and long-lasting disease experiences imply close interaction in care, are prolonged, permanently require continuous care, and dependence on the health system. They open a break in healing-oriented knowledge, and they must present to the common knowledge the possibility of stabilizing what can be destabilized at any time – whether due to clinical condition or dependence on medicines and equipment. This paradox of keeping stable the unstable, the unknown, translates into continued symptom management and control. If these situations of disease are marked by uncertainty in this circuit diagnosis/prognosis/treatment/cure, they awaken the need for interpretations that provide meaning to this unequivocal experience of living life with and despite the disease, for those who coexist and live with, for the equal and informed³.

A perspective into this field requires a position of proximity to first and second person narratives, which include revisiting them in light of the concept of moral experience⁴⁻⁷ and affection⁸. In the paper at hand, our universe finds first and second person narratives of those who live with and closely care for people with rare, prolonged, long-term diseases, and those who cannot be rid of⁹⁻¹⁴. First-person narratives are understood as narratives of those who experience sickness in their body. Second person narratives consider the narratives of relatives, who develop a daily intimate care, with the proximity that did not occur through the technical task of caring, but bonds of consanguinity. We accessed these experiences through biographical works where the author holds one of these two stances. I recognize here Castellanos' review of narratives¹⁵, but I try to approach Laplantine¹⁶ in what may be useful in

our essay. Laplantine¹⁶ studies the interpretative models that construct meanings for the causes of diseases, triggering these different positions in the interpretation of what it is becoming ill, with data from a research undertaken with medical students, and literary works where the biographical statements of the patients are shown.

In our essay, what makes the difference between the first and second person is not just the self that narrates, but its position in the face of experience. Although professionals may be close to patients, including the development of a differentiated sensitivity, not circumscribing it to “their disease”, yet their commitment to closeness occurred by choice: through profession. The patients and their relatives did not choose, but this happened to them as an unexpected event. This position against the disease as a choice or not is fundamental to value the first and second person as biographers of an experience that was not chosen to endure.

We shall not analyze the works – in this case, six biographies, four written by fathers and mothers, a fifth bringing in full interviews with seven mothers, a sixth written by a young woman – with decoupages of their excerpts. We will purposely avoid this format. These books support an argument to be developed in a theoretical essay: biographies of life and living with rare, chronic and complex diseases translate the dynamics of suffering beyond life histories, but are organized as ethnographic literature, translating a field of construction and public presentation of an individual. This sense of field – in the light of Bourdieu¹⁷ – calls us to understand that the paths built reveal rituals of interaction mediated by stigmas, powers built around difficult diagnoses, high-cost medicines – which also became actors – and that require hyper-specialists, and other performances by fathers, mothers, patients who reinvent themselves and qualify as experts, vying for speeches and rights, sharing political spheres, and scientific congresses.

The concept of path^{17,18} is fundamental to this view that illuminates such experiences, revealed by the selected literature. It is summoned here because it is a shared, and, therefore, public field of suffering testified¹⁹, either through activism actions that translate into the search for civil associations for support, self-help and mutual aid^{20,21}, or via literary construction, translated into biographical novels.

The strategy used here is an approach with such biographies, promoting dialogues with the authors mentioned earlier, assuming their theo-

retical essay design. In theoretical essays, according to Meneghetti²², unlike the organization and logic advocated by traditional scientific methodologies, direction is given not by seeking true answers and assertions, but by asking questions that can lead to deeper reflections. We are not guided by a question, but wish to connect between present times, memories, and a theoretical field as lenses for exploring arguments.

Our essay's object is a dialogue with six literary works, understood in the publishing market as biographies, considering first and second person narratives about the relationship with situations of chronic, rare or complex illness. We have tried to make an argument: these biographies are public person-building and presentation forms; they represent the possibility of giving a place of visibility to moral experiences, of great public appeal, but which must be recognized in health care and training as political tools for reflection on practices. Thus, they become testimonies, providing less personal life histories and more biographical paths, with an interactionist dialogue among meanings, places, people, positions, stigma, right violations and discrimination.

Biographies as public constructions of testimonies

Honestly understanding the exotic, the distant and the different, the "other" is not limited to finding the difference²³. In our view, this means refusing the stance of tolerance, which reactivates an asymmetry, removes from the other its abilities and powers, reducing people to an object that is tolerated, accepted, because we are or consider ourselves superior to it. We agree with Favret-Saada⁸ in the difference this author makes between empathy and affection. The first – very much desired, conjured up, and even considered as lost – is often called as an antidote to the "dehumanization" of contemporary relationships. Like tolerance, empathy masks power asymmetry, placing one in a superior position to another, distant from him. As we are reminded, *empathy supposes distance: it is precisely because one is not in the other's place that one tries to represent or imagine what it would be like to be there, and what sensations, perceptions and thoughts one would then have*. It is that somewhat common expression that says *I know how it feels* or *I put myself in your shoes*. The opposite occurs in the affections. An ability to be led by experience is established, intersubjectively sharing the effects that become part of the affective interaction. It

is worth asking what experiences could possibly be experienced as an affection considering that there is a place to which one is taken, and that *we must accept to occupy it, instead of imagining oneself there*, when we are bringing rare disease experiences under the spotlight.

As health professionals and researchers, how much do we bear being affected? Or rather, would it be possible to be affected and continue to take care? Or do we need an empathic detachment to this place, different from what it was to an anthropologist like Fravet-Saada, implicated in another profession? We will let this reflection rest for further discussion. In any case, pain and prolonged suffering require a moral response, as we will explore later by conceptualizing moral experience.

Taking the experience with the stranger seriously means understanding that individual particularities are not qualified as natural, but rather as a game that plays out and can be played because that individual is a member of a society, sharing symbols of culture²³. The tradition that people share allows them to recognize themselves as representative of a community, a long-lasting communicative structure. At the same time, as a result and creator, since he/she participates in a specific, unique and unrepeatable historical process, this individual is about tensions that are often revealed in the dimension of otherness, defined here as the relation with what is foreign to him more than simply different. Human is all that is manifested in society and sociability, and our cognitive ability will make us see our humanity in the "other", and the "other" within ourselves²³. Perhaps this portion of the other within us allows us to be affected by moral experiences as defined in the field of medical anthropology⁴⁻⁶.

It is necessary to avoid equating the concept of moral experience⁵ with the constructs so commonly referred to as perceiving and living, when we resort to the use of narratives first, of those living with a long illness, and second person, who cares intimately. These constructs refer to an idealization of what happens to the subjects when they experience contact with certain situations of reality. There is a picture of something direct, immediate, transposed as truth between what one sees and apprehends. That is, perceiving and living are elements that require mediations, and underpin the field of moral experiences. They include interpretations, symbolic mediations, meanings of what that is to someone from what is interacting with the world, essentially intersubjective, and qualified by symbolic interactions.

The “other” we refer to in this essay is not necessarily a person, but a stance held in the face of the search to interpret the unexpected of co-existing and living with a rare and complex²¹, long-lasting and chronic^{24,25}, prolonged disease²⁶: *long-lasting diseases are afflictions that cannot be healed, but controlled with advances in biotechnology and medicine*²⁶. Or, more so, they *disturb the ideas of healing*²⁴.

Experience is built intersubjectively²⁷, and the world of life, per se intersubjective, precedes each one; and every interpretation of this world conjures up a stock of previous experiences, in a relationship where we are in it and act upon it. The author summons a triad, amalgamated by intersubjectivity, articulated in the production of experience: (a) the reserves and sedimentation of individual inherited knowledge, subjects’ own experiences, their educators, the practical or theoretical nature; (b) the typicality of everyday life, which becomes common, dominated by previously established models; and (c) the structures of pertinence that allows individuals to produce a control of the various social situations, built on stocks of themes, interpretations and motivations to which they are linked in the experienced interactions. And it is in the everyday world that the self is experienced as the ‘author’ of its activities: we live the same world as people around us, establishing a common time experience that is shared with others.

Resorting to Schutz²⁷ to relate experience and intersubjectivity, we return to Kleinmann and Benson⁵ to understand the meaning and strength of the concept of moral experience in the interpretations of the context of first-second person narratives about coexisting and intimately living with rare, complex, chronic and long-lasting diseases.

We assume that illness rests in a body that is a creative source of experience. The meaning of illness is intersubjectively established with narrative strategies functioning as locus for the exercise of reflexively reworking the experience of illness. As social practices anchored in public spaces such as blogs, Facebook pages, and biographies, they can channel the behavior of illness, providing an articulation of a set of meanings that associate illness with ancient and resistant fundamental cultural values of civilization, serving as a repertoire for new diseases or medical classifications.

The experiences of long illness imply continuous and intimate care, and carry with them the images of terminality and suffering, and may also imply hope, happiness, as a possibility of reinven-

tion and creativity exercise. They are defined in a discourse with moralities, referring to values, rooted beliefs, ways of understanding how to address and elaborate their meanings, combining practices for and in life.

When describing certain experiences as moral, Kleinmann and Benson⁵ highlight their inherent value. Valuing means assigning value to produce meaning and sense for oneself in the world through interactions. Interpretation emerges as a way of assuming that something is profoundly interacting, and at stake. Coexisting and living intimately with the experience of rare and long illness means recovering many unknowns and uncertainties, fractures in what is known, with the feeling of being sometimes unique in our history. As the authors remind us: “The concept of moral experience also makes disease part of a broad category of personal and collective hazards and disasters. Life pushes people into unpleasant circumstances and confounds conditions. The enigmatic disturbing life realities: divorce, death of a loved one, injustice and discrimination, dead end jobs, terrible relationships with supervisors, unemployment, bankruptcy, serious accidents, disability, political deprivation and alienation from a community of faith”⁵.

In this unnamed definition, but present in the possibility of interpretation, we should consider that the condition of not choosing, and often the lack of family histories of rare illnesses, leads us to an interpretation about the feelings of having been invaded, surprised, and violently taken by something that does not belong to us. If this diagnosis comes as a condition of a son or daughter, at birth or in early childhood, the image of a violent event emerges as the meaning of the unexplainable that does not coincide with the image of healthy childhood, whose routine would not include being a frequent user of health services, or living in a hospital from birth for a long time. This sense of violence can still be triggered when the state does not provide the conditions for access and high-cost treatment.

Good⁶ anchors the definition of moral experience in the discussion about the construction of the rationality of medical students. This author argues that the daily world of these subjects is built with objects that *are not part of our daily world*. This world consists of a triad: seeing, writing and speaking. The body they speak of addresses tissues at their organic and molecular level; it is reconstructed as a medical body. A dehumanizing deconstruction of the person takes place, only to be reconstructed from the medical

perspective, which identifies it as a case, a patient or a corpse. This is not the experience of intersubjective interaction, but of minimizing the interactional dimension. Such a moral experience will only approach the moral experience of illness as explored by Kleinmann when the fractured meeting of the knowledge previously designed to heal, resolve and decide takes place, and this field of the unknown in the face of what is rare and complex.

In conceptualizing moral experience, we summon a situated experience, understanding which interactions underpin the symbolic game that will make intersubjectivity act more or less, to recognize or isolate it, in its relationships with inherited and negotiated repertoires, typicality and pertinence. This is how we can see differently the experience that turns the sick person's ailment (*illness*) into a doctor's ailment (*disease*).

The meaning of moral experience is intertwined with what is common, shared, and moral experiences of chronic illness are to some extent biographical disruptions²⁸ and reconfigurations of paths in the private and public world with learning and new connections²⁹.

Regarding the concept of path, we conjure up Montagner³⁰, supported by Bourdieu¹⁸, differentiating studies on paths from life history studies. Montagner³⁰ believes life history studies feed a *biographical illusion*, a teleology, which would less correspond to the experience of the lived. It does not imply a line, but a construction of comings and goings, where events do not follow a chronology of calendars, but an assignment of meanings. According to Montagner: *Pursuing a path means following the historical unfolding of concrete social groups in a social space defined by these same groups in their battles by setting limits and legitimacy within the field in which they are inserted*³⁰. The writing of biographies disputes legitimacy with other narratives about illness, which circulate and substantiate professional formations, mostly still referred to the discourse distant from moral experience¹⁸. The biographical situation of chronic illness dialogues with other biographical stocks – Schutz believes that, using the idea of an earlier repertoire of learning that articulates different locus of sociability – and weaves public and private situations that transcend biographies and reach the concept of paths as proposed by Bourdieu. We assume along with Bourdieu that paths are the constructed result of a system of the pertinent traits of an individual biography or group of biographies.

Biographies and their narratives are shown as public forms of individual presentation and con-

struction that is presented as testimonies, as attributed by Boltansky¹⁹: *Witnessing is committing oneself to another person and to invite this person's testimony [...] the issue of testimony is linked to two other issues, namely, suffering and truth*. This moral authority of the truth of those coexisting intimately with a person with rare disease, or living with the disease, is forcefully reaffirmed, reactivating processes of affection.

The theoretical argument that supports this paper recognizes the value of public testimonies, built as biographies in the publishing market, as a field of knowledge that allows access to moral experiences of illness. These reveal ways to construction and public presentation of people, in paths of social interaction where they dialogue, namely, diagnosis, stigma and rights.

Methodological construction: invitations to retrospection and reflection

Methodologically, we recognize that in the face of people who live with and coexist with rare diseases, one must resort to a path of knowledge production engaged and committed to their testimonies. To this end, the metric and the production of numerical data rest in strategic positions, and are invited to present themselves when it is necessary to triangulate methods, complementing knowledge. We invest in methodological resources that allow us: *Adopting a reflective and retrospective posture is inherent in an interview situation, in which the subject is invited to consider himself or herself as an object of reflection. This tends to induce a new description of past events and inner states that have accompanied them, in calculable terms, even as a strategic action, which closes access to the reality of the situation as it presented itself to the people involved at the time*¹⁹.

The idea that also mechanisms of reflection and retrospection are triggered in biographies is added to the previous passage of the author. The author of a biography dwells on his own history to interpret it, producing a public conversation with an anonymous actor. If the participant is anonymous in academic research, the names and surnames are assured in biographies, committing to the reconstruction of a testimony. Boltansky¹⁹ says the testimony allows a concern to be shared, and the suffering that dehumanizes, to take on human dimensions.

Triggering memories, externalizing them, means producing an interpretation, and when communicated, can become raw material for a hermeneutic exercise. This was the hermeneu-

tic exercise that acts as an intermediary for the interpretation of narratives, understood as testimonies, fruit of interactions and negotiations between practical and symbolic language orders that organize and sustain identities and guide behaviors in public places and social life^{31,32}.

We do not grasp people's experience directly, we require mediations, which translate into biographies, filmographies, novels, and travel diaries. In contemporary times, people in the virtual environment of Facebook and Google appear on blogs and group websites. The collections of academic research gather these narratives of experiences under the aegis of anonymity and rules of regulated access. The reader will be introduced here to a theoretical dialogue that triggers six books, whose biographical support values their experiences related to living, in the case of Dachez¹², and coexisting with sons and daughters with rare, chronic, complex diseases and syndromes, some known, and others less so⁹⁻¹⁴. We stress that we do not intend to cover the entire universe of biographies related to the theme of life of and with people with rare diseases. But we emphasize that the central objective of a theoretical essay is experimentation. As Larrosa³³ inspires us: *the essay is the experimental mode of thought, the experimental mode of a writing that still pretends to be a thinking, thoughtful writing that still produces itself as a writing that provides food for thought; and lastly, the experimental method of life, of a form of life that does not forsake a constant reflection on itself, a permanent metamorphosis*. This definition of essay as a possibility for reflection is in tune with a text that one wishes to open, respecting a biographical material that represents the action of people who boldly throw themselves into the world, with a voice and a testimony. Larrosa³³ also argues that we trigger a thought in the present and for the present, assuming the condition of the essayist, to value a thought in the first person, which is not absent from a critical distancing, and is related to reflective thinking.

Synthesis of Biographies as Moral Experiences and paths in a force field

The six read works organized in the Chart 1 place them in basic elements. Our challenge is not to deprive the works of their charm, emotion and intensity, but to drive them in a way that fulfills the function of also disseminating them as references in the academic environment, in the space of the humanities, within collective health. To this end, we call on other authors who will

work on the moral experience of suffering and illness through the lenses of social forces, having them in the background (Chart 1).

Reading these books did not seek to make them objects of formal analysis, but to allow a dialogue where the moral experience of coexisting and living with long and prolonged rare or chronic illnesses are structured as biographical records referred to a field, gaining in duration and launching into a world larger than the author's original experience. Our perspective sought to illuminate them as testimonies¹⁹ that, made public in an editorial market, can turn out to be public paths¹⁸ unveiling an interactional field and triggering other interactions.

We illuminated these works as components of a field where the concept of moral experience is at the core⁵: something that connects existential fractures to a set of evaluations in the intersubjective game with long-standing values and beliefs. The field essayistically constructed here is the field of biographical literature, which operates as an ethnographic literature by allowing access to first and second person narratives related to emergence of a rare, chronic and complex illness situation in one's own life or in that of a child. Its contexts lead the reader to travel within Intensive Care Centers, where white walls, sublimated desires and intensities lead back to childhood memories⁷; to the home environment and the reconstruction of oneself as a work, accepting the challenge of building a special school that caters to the child and other "equal"¹⁴; to a dialogue with the strangeness and body-reconstruction pursuits challenged patterns, and it rediscovered possibilities in a growing child that appears autonomous beyond predictions and stigmas¹¹; to the reconstruction of a father facing a daughter whom he clearly says was not what he expected, makes him reinvent his perspective, finding in peers the possibility of loving the unexpected¹³; in the interviews with seven rare mothers, with the possibility of a dissonance that could be found in the statements about learning, fatigue, but also about the right to choose not to have a child with rare disease, if this diagnosis had been provided before⁸; and finally, the radical difference is gradually withdrawing from the scene of impotence to gain, from the access to a diagnosis, a name to make sense of what was only strangeness, allowing it to reach out other "equal", reaffirming working relationships, and writing of a blog as a place of sociability and meaning¹⁰.

As a field, in the Bourdieusian sense, struggles for recognition and power, here interpreted

Chart 1. Characterization of Works.

Work title	Year of publication	Style	Disease	Relationship with life
<i>A Diferença Invisível</i>	2017	Comic-strip biography'	Asperger's Syndrome	Living with
<i>O que é que ele tem</i>	2016	Biography	Apert's Syndrome	Living with as a mother
<i>Autismo e família: uma pequena grande história de amor</i>	2001	Biography	Autism	Living with as a mother
<i>Mães Raras: essas mulheres fortes</i>	2018	Full transcript of interviews with 10 women, mothers of sons and daughters with rare diseases. Each interview is preceded by a brief biography of the mother, with observations and impressions of the author.	Varied rare Syndromes	Living with as a mother
71 Leões	2018	Biography result of a diary that reports the 71 days of hospitalization of a child in an ICU.	aHUS	Living with as a mother
<i>Não era você que eu esperava</i>	2017	Comic-strip biography	Down's Syndrome	Living with as a father

as power, interpreted here as retaking the place of speech³⁴, commonly called empowerment are at stake in these trajectories. The central struggle here is between the first and second person authorial discourse in the face of the moral experience of being ill, and the third person biomedical discourse, which may justify an artificial isolation of the disease from the life context in which it is anchored. The incarnated diseases in their lives show people with new surnames, referred to places they come to and who see them as “properties” of hyper-specialized knowledge, concentrated in the Institutes of Research, Education and Care. These surnames to which we refer come to ask questions about what he/she has and which names are difficult to pronounce, which are shaped as complex diagnoses, where the mediations for care refer to high financial, emotional and social costs.

We point out that this literary field gathers elements that are operators of: (a) voicing places³⁴, dissonant of a hegemonic discourse that reaffirms technical knowledge, to the detriment of a supposed ignorance of common knowledge, resuming the authorship of experience and path; (b) vocabularies that produce the place of the expert³⁴⁻³⁶, articulating the first person who lives and coexists as a relative building the moral experience of chronic illness; (c) moral au-

thorities³⁷, denouncing state violence, based on learning from long-term sufferings that produce a power to confront discrimination, addressing and even refusing the idealized, almost sanctified images of the *special mother*, which allows one to speak of abortion, rights and desires beyond the pitfalls of guilt; (d) political militancy and activism by producing referral, supportive networks that transcend the self-help movement, raising mutual help^{20,21}. Not only peers or similar living and coexisting with illnesses, but the unique, informed and technical allies that may be in the legislative, health, education, and legal spheres operate in these networks; (e) confronting and denouncing state violence when not choosing to have a child with rare disease means relying on compensatory policies to ensure health in view of the many costs of such life.

The field of ethnographic literature of those living with rare illnesses reaches the public sphere and amplifies one's voice, the antidote to face invisibilities and secrets. As Misse et al.³⁸ remind us, when interviewing Veena Das: *It is necessary to include the links with the political and professional processes that shape them* [the varied cultural and historical styles of suffering], *to inquire about how violence is present in individual and collective experiences, and how new technologies renew the meanings of pain, grief, and also life and death.* To

this end, there is no way to isolate what people write from a set of forces where their testimonies connect, such as very frequent arguments of violence survivors of not choosing to have a sick son or daughter, as well as themselves living with a disease, and still facing social discrimination, the absence of the state, denials of rights, struggles for high-cost medications and technologies, and ongoing treatment.

The biographical literature highlighted here operates exemplarily in these associative symbolics³⁹ supporting a reading of the suffering transcending the private, individualized environment.

This literary testimony contains an associative symbolic to: *understand the moral foundations that condition the desires of individuals to be together and share common initiatives, as if it were something absolutely natural, founding experiences of dignity in everyday life, which allow not only objective rights, but above all subjective rights, for each individual and group*³⁹. We believe that a reticular rationality should be assumed, where gifts and counter-gifts, symbols of association and solidarity, may circulate when these words circulate as biographies in the publishing market.

An articulation between macro and micro social processes occurs taking the perspective of social exchanges via the Theory of Gift⁴⁰. The connection between these processes occurs through the symbolic circulation that resumes the discussion about associativism, claiming a strategic place for intersubjectivity. In the case of a discussion of the arenas that are organized and organize public interests and discourse about “rare people”, it is worth asking how the symbolism of having a rare disease, and being identified as often radically different from most people, can connect symbols of increased identifications and solidarity, as we have seen in Dachez¹² and Novaes¹⁰. The provisional answer comes from what is already circulating in the discursive field of people with rare diseases, which is that disease is only an aspect of their lives.

Some moments reveal a persistent idea of asceticism through suffering. But we can no longer say that this is the only perspective to interpret this experience. Some sociability mechanisms operate and touch deeply, but also cause many strangeness. This literature works as a specific symbolic capital in a set of beliefs about life, death, health, illness and even violence, where for example women who take the place of mothers of these children, adolescents and young adults can sometimes be more than mothers, reviving

work and schooling projects, refusing the place of heroines or special women.

Such a definition setting urges us to recognize that there is a difference when it comes to women and men, fathers, mothers, grandparents, uncles or aunts of children and adolescents with disabilities and rare and complex health conditions with an activist or militant profile, with symbolic capital built intergenerationally and intersectionally, and those who seem to build themselves as biographers of a life of their own, isolated, deprived in suffering. This relationship of an activist identity, forged at the interface between private and public life seems to be somehow liberating. The book of Novaes¹⁰ stirs these reflections.

The political activism represented by relative associations allows the emancipation of pain and loneliness deriving from non-choice. Having a child with a rare disease brings them closer to the exercise of finding a place for themselves in the face of the violence that this represents in the absence of the state, the poorly articulated or nonexistent service network for rehabilitation responses and intersectoral construction. The place for these children and adolescents in day-care centers and schools must be disputed facing the attributions of negative discrimination that triggers stigma³ as a destination linked to the abnormal, dialoguing with a capacitist discourse⁴¹, which hierarchizes the disabled body, submitting it to a standard model. This submission justifies symbolic and physical violence, and disrespect for rights.

Pátron⁹ and Toulmé¹³ urge us to reflect that the place for oneself as a mother and father is being built on a path that traverses the boundaries of unfeasibility, concerns and uncertainties surrounding a terrifying rare diagnosis, and which is made up of decision-making processes that reveal the existence of children and adolescents who affirm the possible. This path unfolds in institutional spaces where clinical care is provided for the health of their children and symbolic capital on social support, rights, support meetings, Facebook groups, websites and blogs of associations.

Keeping the differences, Vianna and Farias³⁷ locate the condition of mother as an element of moral authority in political acts. They walk *between personal pain and collective causes; between sufferings and rights; between different forms and dimensions of mourning*. Moral authority as mother being a political actor implies public denunciation.

Mothers of children born with rare diseases fight for the right to exist and have access to the

health of their children, elaborating the mourning of a child without abnormalities, whose disabilities become testimonies, facing negative social discrimination. A financial but also emotional cost underlies preparing difficult news, unfamiliar diagnoses, overcoming and reacting to social discrimination about the differences that mark body, behaviors, and development. It is about facing the words of professionals who attributed a low survival rate, and address the challenges and joys of seeing sons or daughters growing up, reaching adolescence, wanting to exercise rights to choose that involve facing sexuality and reproduction.

Novaes¹⁰ provides us with a hybrid discourse of the “heroine mother” and the “militant activist mother” in the transcript of interviews with seven women who are also mothers of rare disease sons and daughters. When she defines the term “rare mothers”, she states that *ruling out the drama* is the quality of these women. Moral authority in caring for their children is reaffirmed by research such as the one conducted in Brazil by the Baresi Institute in 2012, where about 78% of fathers abandon the mothers of children with disabilities and rare diseases before their children complete five years of life. The author situates in the 1980s the so-called emergence of the rare mothers’ movement. This movement seems to sew experience, path, and a place for themselves and their children as a public identity.

The school becomes the arena of great struggles for parents of children and adolescents living with rare and complex chronic diseases. Avelar¹⁴ resumes in its path the challenges of a diagnosis such as autism, with associated seizures, in these school spaces. In this path, moving to another city, searching for specialists and fighting for the legitimacy of a knowledge built on experience, are

revealed. In a path seeking peers and guarantee of rights, it creates a special school. Importantly, these children inaugurate the experiences of their mothers and fathers to coexist closely with situations of rare, complex and chronic illness. These children trigger unwillingly the construction of hybrid knowledge, which articulates health, education and social rights. The trajectories are not personal and private, but require public dialogues in the fields of many disputes between relationally situated and interested actors.

Final considerations

The biographies, made testimonies, do not seek to conceal the author, but instead to assume names and surnames. In tune with the concept of paths, we see elements converging that are not enough as personal dramas, but become possibilities to return to fields of symbolic struggles by affirming the diversity of this moral-like experience. We cannot leave aside the discussion about hyper-specialized knowledge that can reduce the experience of illness, to a clinical entity, while family members and people living with these illnesses do not give up taking up this knowledge for themselves, producing a hybrid vocabulary which combines moral experience and scientific knowledge.

We can investigate other agendas to see how they build moral experiences of illness, locating the violence to which they may be subjected by being men, women, blacks, whites, privileged or subalternized economic classes and schooling. The question is whether these intersectionalities are recognized or are obscured by the challenges of a life mediated by moral experiences of illness. Associativism is another public form of person

presentation, and can generate symbolic networks that find associations with different causes, but gathered around projects that recognize diversity.

It should be inferred that such works triggered within spaces and curricula of training of health, education and law professionals could promote bridges to learning based on moral ex-

periences, made public ways of accessing first and second person voices. If biographical literature reveals moral experiences, when made public as paths, these mobilize shared meanings about rare illness, life, death, and violation of rights. As ethnographic literatures in this field, they are public forms of testimonies that trigger sensitivity and rationality.

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