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Rare diseases and the associative dialogue: resignifications for moral experiences

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Abstract *This paper aims to discuss the experience of relatives of children and adolescents with rare diseases as a moral experience. Moral experience is characterized by suffering that is socially interpreted as a catastrophic event, mobilizing resources for signification and meaning that allow the reconstruction of identity, the appreciation of itineraries from a rare diagnosis, as well as the search for peers. Thus, the construction of relationships of recognition, alterity, and belonging is fundamental. From a symbolic interactionist perspective, the results show two significant cores: (1) shock as a surprise in the face of an unexpected diagnosis, leading to the search for peers and promotion of social recognition; (2) the cost involved with the course of a rare disease that implies a care work and the acquisition of associative capital as a possibility of strengthening and building the social capital of health care.*

Key words *Rare diseases, Children and adolescents, Moral experience, Civil associativism*

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Introduction

We discuss the context of chronicity with the moral experience of rare disease through a double movement: 1) that of organized civil society that acts in the face of stigma, formulates campaigns, promotes visibility and affirmation of identity; 2) the quality of bonds, networks of reference linked to the movement of association and dialogue with the State, the determinant actor for the recognition of rights. Civil associations of users and relatives potentiate the stocks of moral experience, promoting collective meanings, shared knowledge, belonging, and a sense of alterity.

Our argument holds that relatives and people undergoing moral experiences of rare illness benefit from associative membership spaces. We recognize a perspective in the field of Humanities geared to the experiences of relatives and people living with rare diseases[1-6]. Various authors[7-10] open windows for reflection in the field of associativism – where the so-called expert patient influences politics, pressures public powers, and debates with experts.

The National Policy of Comprehensive Care for People with Rare Diseases (Ordinance Nº 199/2014) recognizes the sentence "rare diseases", removing the particularity of diagnoses, gathering what is common to definitions of what is "rare", and the needs that diseases that reach 65 per 100,000 people can demand. This policy has advanced in the discussions with associations, aimed at people with rare diseases, regardless of whether they are genetic or not.

We speak with classic authors of interactionist sociology who highlight physical body marks as essential mediators in the construction of public identity[11-13]. In this case, Goffman points out that diseases or disabilities are face mediators. "Equals" are those who carry these marks, while the "informed" are those who adhere to the cause, such as professionals, friends, and relatives. What binds them together is not "being equal", but constructing the "common" in the symbolically situated differences that promote mixed interactions. These, by the way, are strongly configured in reference networks where health professionals from specialized institutions provide diagnoses, vocabularies, and treatments that become appropriable, through other relationships with the knowledge of the Internet, and other families in interactive and treatment environments.

Giving visibility and mobilizing a public existence allow "Rare People" to be recognized. The perspective of unique expression, gathering more than eight thousand diagnoses is put on the agenda in the sentence "Rare People". Even knowing that this social identity can dialogue with more general and recognized ones, such as people with disabilities or with chronic and complex health conditions, there is an affirmative claim to the Rare character of the person.

The concept of experience is not confused with perception or living. We have made a point of qualifying the experience of illness in oneself or in someone with whom a bond of intimacy is established as a moral experience[14-16]. This moral qualification attributes to the experience of rare illness – enduring, with incorporation of institutional and familiar control routines based on high social, emotional and physical costs – attributes of a catastrophic event, mobilizing significance and meaning resources that allow for the reconstruction of identities, valuation of new itineraries based on a rare diagnosis and search for peers.

The idea of moral experience articulates fear and what is desired with a series of obligations, the result of social interactions. Kleinmann[15] affirms that these interactions coexist with pain and disaster in an environment where not only power and threats are distributed unequally but are also unfairly responded in the real world of human pain. This consideration intersects several markers and causes us to trigger the morality of experiences, moving from the ideas of perception and experience towards socially constructed interactions, one effect of which are associative movements and rights activism[17-19].

We shed light herein on a set of analyses that highlight a perspective on rare diseases that compromise families, in associative bonding environments, with the care of their children. These same caregivers or people living with these rare and long-term illnesses may often be in a context of activism. This perspective of chronicity traverses and underpin our reflections on rare illnesses[20-29], making us return in this dialogue to people's moral experience, and not to the disease object in its medicalized realm.

Methods

The research approved is linked to studies of interactionist and symbolic situationalism[12,13], which prioritize micro-sociological environments, sociability, and the construction of identity brands. We sought to meet relatives linked to

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associations, in spaces such as specialized hospitals, rehabilitation services, meetings and associations' headquarters, public information sites, and social media.

Careful approaches were required since these were moral experiences of illness, suffering, creation, affirmation, and discrimination, which led to prolonged field exposure, involving association meetings, conversations in waiting and hospitalization rooms at a hospital of reference, as well as participation in public hearings and marches. This movement took place from February 2015 to December 2017 and remains a commitment of the research.

Three focus groups were conducted, in which relatives linked to participating associations were invited to a group conversation, which was recorded and then transcribed, submitted to decoupage and interpreted. This process involved 30 participants linked to civil associations, namely, National Association of Imperfect Osteogenesis (ANOI), Rio de Janeiro's Association of Mucoviscidosis (ACAM) and Guardian Angels – Association of Friends and Relatives of Mucopolysaccharidosis. These associations were chosen: a) for their role in guiding/supporting the families that receive these diagnoses in reference hospitals in the State of Rio de Janeiro (RJ), dialoguing nationally with other venues; b) for their representativeness in public spaces such as rights councils and public debate spheres; c) because they are references in the organization of events that gather other associations of rare patients of Rio de Janeiro.

Regarding data interpretation, we sought in the symbolic interactionism the references to interpret the situations that underlie the moral experiences of illness. We gathered them in two axes, namely, that of shock and that of the social cost linked to the debate on trust, recognition, belonging and alterity. Diagnosis, treatment itineraries, belonging, and mixed interaction paths – which encompass donor circulation circuits – are built-in knowledge process and self-recognition as moral authorities. We purposely do not move the excerpts from the statements in the focus groups of the text as a whole. We sought to articulate the meanings with the analyses undertaken, considering that it is essential to locate those who speak from their position of gender and generation (**Chart 1**).

Discussion

Regarding rare health conditions – unlike other studies with chronic health conditions of higher prevalence in the population or that are better known – no repertoire of knowledge shared by professionals of the different levels of health care and by the general population is available. This demarcates a vital difference that interferes with the diagnosis and treatment itineraries, the capacity of people linked to the family networks and institutions that dialogue with them, to understand, name, and have a representational repertoire to address their challenges. Articulating this proposition to the concept of moral experience, we highlight two axes: (a) shock as a biography-linked emic category; (b) non-choices as a component of moral experience linked to the costs of the rare health condition.

Shock as an interpretation of the moral experience of a rare illness

It is common to establish a framework for the "before" and "after" in the narration about the historical background, which coincides with a time frame where the past can be a reference to healthy people in the family, with the inexistence of previous experience to dialogue repertoires. Hence, the emic category of shock seems recurrent, biographically placing the experiences with the diagnosis: to a grandmother, it is the family's non-recognition of diagnosis, while to young mothers, it could be possible disagreements between intensive care projects and perspectives of personal fulfillment.

We resorted to Epele[30] for whom care is *set of bodily, binding, subjective and political technologies*. It helps us to reflect on how the experience of caring, related to the tragic realms of existence, overflows in power relations unequally distributed in a plural complexity, with intervening knowledge, social networks, technologies, tasks, and bodies. The expression of shock gathers much of what it can refer to care, disruptions, institutional demands, and unanswered rights, mismatches, re-encounters, and reconstructions. Shock does not correspond to a pathological condition equivalent to medicated panic or anxiety and depression symptoms[31], but it is the expression of surprise, that older women are unable to explain, while it represents a turnabout in the path and future projects of younger women.

This shock is linked to the biographical rupture[32], establishing a transition in the histories,

Chart 1. Statement and profile by generational and gender markers.

Identification	Generational and gender markers
Statement 1	father of girl with Cystic Fibrosis - CF
Statement 2	grandmother of three girls with CF, referring to the first born under this condition
Statement3	young mother with higher education and daughter with CF
Statement 4	mother young son with Osteogenesis Imperfecta – OI
Statement 5	young adult man with OI
Statement 6	mother of boy with OI
Statement 7	young mother of a daughter with OI
Statement 8	adult woman with mild OI and suffering from invisible eye pain
Statement 9	father of a boy with MPS
Statement 10	mother of a boy with OI
Statement 11	mother of a teenager with MPS, living with BPC grants, without companion
Statement 12	mother of two girls with MPS
Statement 13	mother of an adolescent with MPS
Statement 14	young woman mother of a girl with CF, higher education level, with career interruption and a newborn baby under diagnostic investigation
Statement 15	grandmother of a girl with MPS
Statement 16	father of a young adult with OI
Statement 17	mother of a boy with OI

a milestone for grandmother in the search for previous experiences, and for the young mother, in building another place for herself and her child in life and treatment itineraries. Reflection on this process occurs in interactions with the assignment of value, idealization of maternal care and its demands, justification, and naturalization of paternal abandonment.

This rupture perspective inaugurates another life path. Dialoguing with the concept of biographical rupture[34], Herzlich[33] points out that the content of rupture does not always point to losses, but may mean discoveries of skills. We highlight the stories of women and men as mothers and fathers of people living with rare, chronic and complex diseases, who organized civil associations, wrote books, founded special schools[34], created blogs[35], and became references to public statements.

Shock is an alarm, realizing an alert posture that, on the one hand, concerns the recognition of the unusual, that they *never had anything, no problem in the family and life expectancy was very short* (statement 1), and on the other, the expectation of care-related costs, saying *we have no funds, no funds at all* (statement 2).

Shock means triggering a time-related antecedent that refers to the *Via Crucis* to seek diagnosis, which is defined after lengthy investigations and gives rise to a movement to search for its meanings on the Internet. The so-called low life expectancy (statement 3) qualifies *shock*.

This feeling of being unique instead of different is associated with the strong images that *we have no ground to tread on ... a bombshell, so impactful ... the only mother in town, I was lay, blind, I didn't know anything* (statement 4).

First-person experience dialogues with emotion, catalyzed as a shock, is not restricted to an individual singularity. The primary choice is coping with emotions as a strategy, where interactions and interpersonal exchanges are at stake. The first-person of the self that answers the interview questions, dialogues with the *you*, the *we* and the *them* that mark the subject's experiences in the world. We adopted Laplantine[36] and Mauss[37], articulating the experience of illness and moral narratives, considering that exchanges and symbols make trust/security/distrust/hope coexist in this field of search for health care, which even seemingly contradictory, speak of how distressing and reconstructive this shocking experience can be.

First-person retrospection allows recognition of a place by someone who does not submit to the disease but manages it. The role of parents in guiding children is highlighted; *I have had this disease since I can remember... you cannot do the*

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same things as other kids, but you do it your way ... you're the best person to say whether you can or cannot do (testimonial 5).

Understanding the realm of the disease is not news at a specific moment in the course of life, but is a process that accompanies development as a child and subject of social interactions. The moral experience of living with a rare illness is qualified as the ability to grow by mastering own illness. We highlight that the interviewed families, with strong associative ties, evoked fields of experiences where suffering drove the search for peers, building trust, qualified care, and political leadership.

Putnam[38] helps us in this discussion while reflecting on social capital. Social capital is a resource generated in social networks, exchanges between people who identify, in their interactions, common elements, values, trust-promoting standards, recognizing it as a fundamental element for health care.

In the context of debates about trust and its attributions, especially concerning having an unknown or rare diagnosis, pilgrimages are unevenly distributed, creating fractured relationships, where doctors and health professionals are also involved in research rituals, with concerns and uncertainties. Thus, the "diagnosis/treatment/cure" circuit opens up to "diagnostic uncertainty/rare condition/chronicity/insecurity/distrust".

Non-choices and costs in the context of moral experience of a rare illness

Not choosing the disease as a destination, but recognizing in it an aspect of life, is a learning that can foster the search for peers, increasing trust relationships. The obligation to take care of oneself, not only in the context of medication taking, regular visits to rehabilitation but as a subject in the institutions, building sociability and work projects are found. Living with a rare disease is living with many uncertainties, suspicions, and emptiness: about diagnoses and their names that often occur late or never materialize, or even about future projects.

The association between care and its cost does not shy away from essential reflections where *lack of knowledge is a huge cost in life* (statement 6), or in the weak support network so that women can continue their careers, *many [mothers] stop living altogether, can't work, and don't have someone to help out* (statement 17).

Alves and Bueno[39] point out that women are the primary caregivers of these children, and when they are not caring, because they have been able to maintain work relationships, they hire other women in a mostly female job.

In this realm of choices, we resort to the discussion of Hirata's care[40]. We highlight the position of women in the face of care that is a "genderalized" work. The predominance of women in children and adolescent care, more specifically, children with rare and complex health conditions, implies a universe of many interdependencies. This care work dialogues with the sexual division of labor in which gender relationships and ideals of masculinity justify the lack of men in the world of care.

Another meaning associated with cost refers to heredity and the possibility of not transmitting an inheritance, considering emotional costs: *prejudice, and stuff like that... does not want to live this, to take the risk, and adopts* (statement 5). But dissonance emerges in the project to avoid heredity of rare diseases *regarding the issue of adopting; I think differently; I want to adopt an IO because I have heard reports of children who are abandoned ...* (statement 7).

Also, more so, *I don't see this thing: "I won't put my kids with the same disease as me into this world"; it just won't happen. What I think is as follows. I'm here. "I'm in life; I went through all this ... Then I will restrict, I will choose, "I don't want to have a child with IO!"* (statement 5). Adoption, genetic counseling, and reproductive technologies also appear in this contemporary environment of living and caring for someone with a rare disease.

For those who do not have noticeable IO marks, a reported cost was not being recognized for the disease and not having social benefits: *That's a cost, the hassle it causes because the appearance didn't show anything. They were looking for what I had there to lift me from the chair so that I could sit down on the yellow chair... There was no disability just because they did not see a disability, only pain* (statement 8).

In the case of this research, having CF does not have an external mark, which is only revealed at times of critical evolution where oxygen dependence leads one to use handheld supplemental oxygen-linked breathing catheters. In IO and MPS, which have varying degrees of severity, body marks are evident with corresponding physical disabilities. However, as highlighted in the previous paragraph, a mild form of IO has no apparent disability, hampering access to rights. This is achieved through the use of special transport seats, queues for the disabled, and investi-

gation for social benefits. Her primary symptom, pain, does not justify her rare condition, and possible disability that would benefit her from using a special seat, operating as a cost to be worked out in the process of recognizing herself as a rare person at interfaces of moral experiences in mixed interactions.

The path to achieving diagnosis is strenuous, hence the importance of early diagnosis through the foot test, which would save the pilgrimage to different hospitals. The clear State's responsibility to ensure the right of access to health, with medicines and treatments is not absent in the statements *it was a struggle,* [...] *no one wanted to take it, not even on a private basis... the doctor said: "I'm afraid because I don't know anything about the disease … "I don't have time to research this*" (statement 9), or recognizing that this lack of knowledge of professionals working outside specialized centers also is a cost, "*thus, this lack of knowledge is a cost to public health.* (statement 10).

The clarity that a pilgrimage is being built – *I went on a pilgrimage ... I went to the pediatrician, she said* […] "*mother, that's normal, you are creating this in your mind". I didn't accept this... her ribs were too large, and she had big hands... foot, big hand, thin leg, long arm: I found it very strange... he sensitized, right? He said: "No, something is wrong". I went to my orthopedist who was already treating my spine, and he said: "mother, look, go there and get an x-ray*" (statement 11) – this appears as yet another aspect of a shared and collective experience in face-to-face interactions.

An exchange circuit breaks down when the doctor – owner of the social mandate about the truth that resides in the "disease/diagnosis/cure" – is situated as a character producing disbelief and distrust. By disqualifying the mother's suspicions about something that might be wrong with her child, he dismisses the power of the encounter, revived at other times by the possible interaction qualified by emotion and sociability networks.

In the relationship with levels of health care, the family of a child with a rare disease operate as informed people who disclose and warn about the disease, including health professionals, *how will he provide the diagnosis if he doesn't even know the doctors? Someone is at home with a child who does not know that he or she has, not even the syndrome because he/she cannot diagnose* (statement 12).

Conjuring quality life means seeking the right to be attended closer to home, but the fear of the unknown that these children represent produces care refusals *I want her to have quality life. Also, how will these children have quality life if we only bring them here? [specialized hospital, let's go to the pediatrician, the scared pediatrician panics, doesn't even prescribe a medicine for the child's headache* (statement 13).

The contradictions of the State regarding the non-recognition of women's rights emerges when *people don't talk about liberating abortion, but they are actually killing our children ... they can kill our children when they lose the right to the medicine... what they're doing is choosing who will live, the perfect ones live and the sick ones die .... I learned to live with cystic fibrosis. If I had another child, if I had the option to abort or not, I would not abort, but I think that one must have the right to know if he/she wants his/her child to come into the world or not, because, this is another one, this guarantee of rights is not being appropriated. [...] Most people are salaried ... Also, what it is to be unemployed and not be entitled to a benefit* (statement 14). Or, the argument of minimizing the condition of rare as a justification before the State ... *it is rare as such, but not as rare as our government turns its back; for example, there [where they live] too, when I walk with X., I feel that way, people's eyes all over me* (statement 15).

There is a debate about reproductive rights in a scenario where the care of a child living with a rare disease demands a responsible and robust state, with the perspective of compensating the vulnerability processes. One must recognize that where economic, emotional and social costs overlap, the "right to be born x right to choose not to be born x individual responsibilities" can be interpreted as a silent state violence mechanism.

In interactions with people unaware of rare diseases – in mixed interactions[13] outside specialized hospital settings – reactions range from curiosity to moral judgment. The father of a boy with MPS reports how much the definite diagnosis was accompanied by shock but also hope. In his statement, hope is linked with halting the progress of the disease, but without *reversing their posture physically, that I think only God can, because I believe medication cannot reverse it anymore* (statement 9).

This father was the one who most insisted on the recognition of disease marks in the body as mediators for postures and reactions of curiosity and judgment. Faced with these reactions, he revives justifications about how rare, invisible the disease is, rarely present *a rare disease is because*

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there are few cases ... they look at them differently. Once, at the ABBR [Brazilian Nonprofit Rehabilitation Association], *it's ugly there, just prostheses, amputated people ... he's so cute, what does he have? .... I choked and said, "What should I answer now?"*

Being able to justify, choke, recover, and try to minimize is part of an explanatory circuit in the construction of a testimony[41], in his public presentation and that of the child. Other elements are triggered in these mixed interactions, highlighting the capacitist judgment, the imputation of neglect of harmful discrimination... *These days, I got off the bus here with my granddaughter. A lady called me and said: "Forgive me for saying this. I see you passing by here with this little girl. I live in front of you. Won't you do anything for this child, will she continue with that crooked leg and will not grow up, won't you do anything?". I said: "Well, her problem is not that, I can't have her leg broken, as it won't do her any good" ... that's not the issue; it's a genetic formation*" (statement 15).

The capacitist logic underpins the boundaries between the "normal" and the "disabled" body, based on able-bodiedness[42]. Capacitism operates as discriminatory rationale producing discourses and practices of exception, justifying corrections, just as male chauvinism hierarchizes men and women, linking the former to the masculinist ideal of power, strength, and dominance, and racism operates by disqualifying certain people who do not correspond to the white standard.

Paradoxically, capacitism appears as one of the possible answers to the legitimate desire to face bad news, the reserved prognoses that can compromise life expectancy. One of the realms of empowerment is linked to hope ... *we would like them to grow up normally, have a healthy life, a normal life ... just like other children. I believe nothing is impossible to God, but I find it hard* (statement 15).

The references that associate hope with uncertainty in the relationship with long-term suffering and the investment in genetic research, contrast with the few treatment opportunities[3]. However, hope for medicines can cover up discussions about reproductive rights[3].

The rarer the disease, the more expensive and necessary medicines, supportive therapies, investments, and sites for therapeutic rehabilitation resources. High-cost medicines promote long agendas of debates, claims, real struggle arenas, where dialogue between the performances of warrior, survivor, and hero take place. Such metaphors idealize and remove humanity, promoting the extraordinary that also reveals a capacitist face. We emphasize that heroes can be both sick people – adults, children or young people – as well as their relatives, and other informed[11], such as politicians, researchers, the pharmaceutical and diagnostic testing industry, and professionals who embrace the *battle*. These warlike metaphors predominate and operate by qualifying the arena where human and nonhuman actors clash[43]. In this case, instead of the warlike metaphor, a militant and engaged performance is imposed.

Part of the medication is high-cost and leads to reflect on the issue of improving *their quality of life; why such an expensive medication no longer has functions? Except just in the respiratory part?* (statement 9). The commercial value should add to the previous rationale a higher power to attack and cope with other complexities and needs of the associated clinical condition.

Scientific congresses are attended by researchers, professionals, industry representatives, and include family and people with rare diseases in these mixed interactions. In this meeting between equals and informed[13], equals engage in mixed interactions with the informed, represented by researchers and experts. Controversy over the enzyme that will treat MPS – a non-human actor that influences the performance of hope – produces compensations: it does not improve bones but the respiratory part. Congresses are the venue that harbors symbols and care goods, promoters of intimacy bonds between relatives, people living with the experiences of illness and researchers/professionals.

Mixed interaction spaces serve as a locus where knowledge, references, contacts, operate as symbolic goods that strengthen the families that attend them as members of civil associations. This perspective includes what Moreira, rereading Martins, and both triggering the Gift Theory[37] in the health area, point out as a "circulation of goods": healing in the reading of Martins[44], and care in the case of Moreira[45]. Still towards the circulation of care goods in a donation circuit, the information and dissemination appear materialized in a non-human actor represented by leaflets *I went there at the Health Post .... they didn't know what it was, the child "is at home". I distribute them wherever I go... at the INSS [National Institute of Social Security] ... and doctors are unaware and don't know ...* (statement 15).

In other words, distributing leaflets about the rare disease of the granddaughter means increasing knowledge, confronting the ignorance that intervenes in the girl's recognition harming her

public existence. In the discussion by Martins[44] and Moreira[45], the gift and circulation of goods occur through the tests provided, diagnoses performed, medicines, but also through words of welcome, comfort, advice, knowledge shared in associations meetings, and that, when circulating, are no longer owned by anyone but provided to all.

Alves[46] highlights that bonds are built in a path of the search for care, where the disease is a construction in which patients, doctors, families, friends, and caregivers participate. In this case, it is essential to reflect our capacity to be affected[47], so as not to limit ourselves to the asymmetry of hierarchies.

Associations are organized as an effect of the gift-giving circulation[37] between equals and informed, where *he* [the doctor who treated at the specialized hospital] *had this view of the need for an association; he advised "why don't you set up an association and so forth?", and we took a while but then left* (statement 16).

The reference role of some women who have learned by taking care of their children and interacting with health professionals, forming associations, gains strength as yet another mechanism that circulates donation between equals and informed, *so it is the importance beyond knowing new mothers; you know the explanation, the moment it is discovered, what has to be done, how one gives the infusion, when he suffered that fracture, the moment of surgery; so at ANOI, they provided us with this step-by-step in their lectures, so participation is essential. The pursuit of knowledge ... less suffering, the same pain, and difficulty, so it is a very valid exchange ... security* (statement 17).

This perspective of seeing references, clarifications, words of comfort and support among families whose children have rare diseases, chronic and complex course, facilitates coping with feelings of being unique, which accompanies the loneliness of diagnostic uncertainties, generating safety. It also enables the operation of alterity and recognition, generating symbols of comfort that underpin the realms of belonging. The place of civil associations – which also taps on sporadic exchanges in informal meetings in health care waiting rooms, blogs, and web pages – allows the organization of actions whose challenges lie in stimulating political participation that transcends pain.

Conclusions

Coping with the rare moral experience of illness through the search for peers, equal and informed in this experience should be read as an associative experience of shared social capital.

The moral experience of rare illness articulates time and space, fundamental elements when triggering the chronicity of living with a rare disease, viewing it as a non-choice, reinventing other possibilities in a field of interactions. The field of moralities in the experience of chronicity and rarity can be defined as the field of possibilities for managing diagnostic uncertainties, stigma, and social capital construction, towards the establishment of trusted networks.

The experience of rare illness as a moral experience brings us to three perspectives: 1) the rare qualifier highlights what is little or not known, and there is no common sense public repertoire to base interpretations, and frequently, even by professionals themselves. This increases social, emotional, and financial costs. Nothing is common or known, and unlike the most common chronic diseases, medications, research, care actions become complicated, and can also be "rare"; 2) the "rarity" highlighted by chronicity, and increased in the search for an "equal", where recognition and belonging are symbolically and materially realized and anchored in political activism, circulating knowledge, interacting in public spaces; 3) The cost of not choosing the rare condition implies reviewing care interactions and intergenerational positions in the reorganization of experience, building other places for children and themselves, revising itineraries and future projects.

Collaborations

MCN Moreira was responsible for the conception, design of the study, and paper review. MAF Nascimento, DS Campos, M Pinto, and A Madureira participated in data review, writing and critical analysis. ACC Costa, LBP Barros, NV Oliveira, DDF Horovitz, AJ Martins, and L Albernaz participated in discussion and paper review.

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