



Low-complexity biotechnology and everyday aspects of “care:” neonatal testing and sickle cell diagnosis in Brazil

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Abstract

The article discusses the link between the use of low-complexity biotechnologies and the diverse notions of “care” involved in the process of diagnosing sickle cell disease. It analyses the stories of four different patients and their families, all collected during ethnographic fieldwork, that illustrate several aspects of the experience of living with the condition. These stories demonstrate the presence of what Mol called the “logic of care,” showing how the everyday use of diagnostic technology is set within life flows that relate to other realms of experience with biomedicine, kinship groups and community networks.

Keywords: healthcare; sickle cell disease; neonatal testing; medical technologies; Salvador (BA).

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The popularisation of biotechnologies within healthcare institutions has been central in contemporary biomedicine. From the widespread use of low-complexity diagnostic tools such as complete blood counts, to the less common use of high complexity experimental technologies, such as gene therapy, biotechnologies are becoming central in the process of diagnosing and treating medical conditions. The popularisation of medical technologies can shed light on the changes that biomedicine itself has undergone, experiencing an increasing specialization of knowledge and reliance on diagnostic technologies. Medical Anthropologists and Sociologists have long studied the impact these changes have had on cultural models of illness and health, on ideas about the body itself, on the (re)creation of social identities (in the process termed “biosociality” by Paul Rabinow and followers), or on doctor-patient relationships (Rabinow, 1992; Hacking, 2006; Gibbon, Novas, 2008), with some authors analysing the effects of the circulation of wider neoliberal-influenced ideas about the “individual” on doctor-patient relationships and on biomedicine in general (Martin, 1994).

Amongst the authors that have recently delved into the changes biomedicine is undergoing, Dutch philosopher Annemarie Mol (2008) developed a theoretical framework to explore how the different ideas about the individual are articulated with the use of medical technologies. Mol contrasts a model of biomedicine that values patients’ “choice” – a concept at the core of neoliberal ideologies of the individual¹ – with a model that values “care.” These models, or “logics” as the author names them, would have very different effects on the practices carried out in healthcare institutions. For Mol, the “logic of choice” is based on the individuals’ ability to choose, after being given all the information about therapeutical options, the course of action to be taken. Two different possibilities are set within this logic, which she relates to two different spheres of modernity: the patient is seen as a consumer or as a citizen. In the first case, medical technologies, including diagnostic ones, would be set within a consumer model, being offered as a product. In the second case, biotechnologies would be relegated to the role of providing enough information to allow the patient, in his role as the citizen that controls his body, to make an informed choice.² In both cases, the burden and responsibility over the course of action taken would rely on the individual and his presumed ability to make a choice.

The “logic of choice,” from this viewpoint, is frequently set in opposition to a “logic of force,” according to which those who are more knowledgeable about the disease – doctors and other biomedical professionals – impose a therapeutic course of action on the patient. In that sense, as Mol (2008) points out, it is obvious that the “logic of choice” is better when compared to a “logic of force.” There are plenty of examples, widely explored by the anthropological literature on biomedicine, that show how the “logic of force” is still present in a lot of biomedical contexts.³ For Mol, however, the “logic of choice” should not be set in opposition to the “logic of force,” but to what she terms as the “logic of care.”

In order to conceptualise this alternative logic, Mol (2008) relates what she terms as “care” to the wider realm of “life,” in its broad philosophical sense, illustrating her arguments with the ways in which technologies for the management and control of diabetes, such as personal monitors for measuring blood glucose levels, or devices for injecting insulin, are enmeshed in a field of conflicting everyday practices and interests. The medical recommendation, for example, to keep blood glucose steady needs to be juggled with diabetics’ lives and the

likelihood that they'll be able to take regular glucose measurements. This, in turn, is related to their familiarity with glucose monitors, their daily schedule and the extent to which both the activities they undertake and the setting in which they are undertaken allow for the necessary conditions for blood measurement.

Under the "logic of care" framework, the individual is never considered as a separate entity from the network of interests, ties and complex social processes in which he is immersed. In that sense, Mol's analytical model has certain advantages for the analysis of medical biotechnologies. Mol (2008, p.5-6) does not consider these technologies as being inherently rational and objective, even when the "logic of force" and the "logic of choice" (both in its consumer and citizen subtypes) persistently portray them as objective and impartial. Furthermore, her approach is also very useful for any analysis of biotechnologies based on the phenomenological conception of experience, given that it emphasizes how biotechnologies are intertwined with practices of care set within a broader notion of "life."

In this article I analyse the practices and meanings attributed to the diagnostic technology of neonatal sickle cell detection, popularly known in Brazil as the "babyfoot test." I follow Mol's analytical choice of not separating medical technologies from "life" (Mol, Moser, Pols, 2010). My main argument is that the impact of medical technologies cannot be analysed only in terms of a reduction of the autonomy of choice of those involved in its use, as certain viewpoints from the so-called medicalization paradigm argue (see Gaudenzi, Ortega, 2012). I argue that we need to analyse how people engage with medical technologies, and with biomedicine as a whole, without presupposing any specific effect. In the case under study, neonatal testing for sickle cell disease in Salvador, Bahia, I show how this diagnostic technology is set within wider notions of "care" of the self (Foucault, 1985) and of others tied to people's broader life experiences. In order to understand what these notions of care imply one has to realise how they are linked to diverse life experiences and life "projects," understood within the phenomenological notion of openness towards the future. I will exemplify this through four stories, all set within the city of Salvador, Bahia, that involve the detection and treatment of sickle cell disease. I consider these four stories as condensing several aspects about the experience of those living with the condition. The stories were collected during fieldwork undertaken between 2005 and 2008, as part of a research project on the presence of sickle cell in the city of Salvador.⁴ During fieldwork, I undertook participant observation in spaces such as the hospital where haemoglobinopathies patients receive specialized treatment, community health clinics in charge of contacting families with positive neonatal test results and later on providing general healthcare for patients, as well as the local Association of Parents and Friends of Disabled People (Associação de Pais e Amigos dos Excepcionais, Apae), a non-profit organisation where children diagnosed with sickle cell and their families receive early intervention treatment and genetic counselling. I also accompanied the families at their local neighbourhoods and homes. All the stories presented in this article are assembled from fieldnotes written during the participant observation research period, during which I was allowed by the families to become acquainted with a slice of their everyday life, both within and outside institutional contexts of healthcare. The reflections presented here regarding the different ways of dealing with sickle-cell diagnosis led me to analytically consider the relation between biomedicine, experience, and life projects.

Public policies for detection of variant haemoglobins: neonatal testing

Neonatal testing started in Brazil in 1976, when the non-profit organization Apae-São Paulo started testing for phenylketonuria (PKU). This initiative was expanded in 1992, including testing for congenital hypothyroidism, into a nationwide programme under the supervision of the Ministry of Health. This early detection programme was transformed, in 2001, into the Neonatal Testing National Programme (Programa Nacional de Triagem Neonatal, PNTN) (Souza, Schwartz, Giugliani, 2002). The implementation of the PNTN was undertaken in three phases, with haemoglobinopathies being included in the programme in the second phase. The PNTN not only regulated the detection of genetic conditions, but also the early medical treatment of babies diagnosed in the programme within a multidisciplinary health unit. This health unit had to count on the presence of medical personnel who were qualified by a medical genetics department to provide neonatal genetic counselling. In spite of this, a lot of families currently do not receive regulated genetic counselling due to the shortfall of adequately qualified personnel working within the PNTN system (Ramalho, Magna, Paiva-e-Silva, 2003).

Current research estimates the percentage of children born in Brazil who undergo neonatal testing to be 84.88%.⁵ The expansion of this type of test presents us with several important questions regarding the meanings attributed to the health-disease process. On the one hand, under the biomedical gaze, genetic hereditary conditions turn not only the person affected by the disease into a patient, but the family as a whole, seen either as potentially affected – in the case of degenerative conditions that only present themselves later in life, or individuals who tested positive for genetic markers for multifactorial diseases such as breast cancer – or as potential future genitors of children affected by the disease (Cox, Mckellin, 1999; Finkler, 2011).

On the other hand, if we look at neonatal testing under the idea of “care”, we need to consider not only the patient and his or her kin group, but also their whole life trajectory and the relationships and contact established with other people and with material objects themselves, such as medical biotechnologies. In that sense, I follow Tim Ingold (2012) in considering the materiality of objects as being part of the “mesh of lines” that the “fluxes and flows of life” consist of. In this way, the focus of the stories that I present here demonstrate how technology and the experience of living with sickle cell disease are transformed depending on the wider life context of those involved with the condition.

Care for the newborn and biomedicine

Ivan is 45 years old, has curly kinky red-brownish hair and fair skin with lots of freckles, an appearance that is locally termed “galego” (literally, Galician). “I have no relatives in Spain, I come from the hinterland, have you heard of Jequié?” Ivan chats with me while her two sons, João, aged 6, and Cauã, aged 5, turn the corridor of the local health clinic into a children’s athletics track. The clinic had mildewed walls and a dirty medical examination table at reception. The patient’s toilet had to be closed down after someone stole the tap. “I came to pick up the folic acid and penicillin prescriptions. Lately we’ve been picking up the

medication here, at the local clinic. It’s good, it’s here in the neighbourhood, I can fit in a trip in between jobs.” Ivan does not hold steady employment, he does odd jobs. “I can fix electrical systems, plumbing, even small renovation projects. I learnt with a colleague, who is a mason, I was his helper for a few months, and I picked up some tricks of the trade.” He didn’t complete his elementary education, but he can read and write, a fact of which he is proud. “My mother, in the rural area, she was always very dedicated to teach us whatever she could. There was no school, I mean, there was, we used to go, but only when we could. We couldn’t go all the time.”

Ivan’s partner, Elisabete, is the one that contributes, with her eight-hours a day, six-days a week, minimum-salary job as a cleaning lady at a local luxury shopping centre, providing a more constant flow of money toward the domestic budget. That’s why it is Ivan who is in charge of bringing their children to the doctor, which causes probing stares from some mothers who are also at the waiting room. The diagnosis of Cauã, his youngest son, with sickle cell disease happened during a period in which he was getting a lot of work as a mason. “A colleague referred me for this job at a construction site. It wasn’t a job with all the rights guaranteed, I didn’t have a formally registered legal contract, but they paid the salary on time, they even provided us with meal tickets!” The diagnosis happened a few days after Elisabete and Cauã had left the maternity ward. “She was still in the *resguardo* [postpartum confinement period]. At the health clinic they said, the lady [the receptionist that handed them the neonatal test result], she said we had to redo the test. And with being busy with work and everything, I forgot. With João, all the vaccines, each and every one, I made sure he took, didn’t forget a single one, but with Cauã...”

A few months later, Cauã had his first pain crisis caused by sickle cell disease.

It wasn’t me who took him to the health clinic, that day it was my wife. They asked her about the neonatal test, and when she came back home, I remembered that I had forgotten to take the baby to redo the test. Everything fell on my head; I couldn’t sleep for three days. I would toss and turn, and my wife talking ‘Ivan, the baby was born like this, the doctor told me, it wasn’t your fault’. But I just couldn’t forget that I had forgotten to take him to the doctor.

Ivan fell into depression and stopped eating. “It was then that my sister-in-law sat with my wife and they told me: Ivan, we are going to get you an appointment with a doctor. If things keep on going like this, you are going to die.” And they forced Ivan to get that appointment.

Doctor Marcela, from Pernambuco. I remember that appointment as if it was today. She examined me, asked me what I had. Doctor, I regret not taking care of my son. What do you mean? I explained to her the test issue, how I had forgotten to bring the baby for a retest, the situation he was in, the crises, how it pained me to see him suffer. And she explained things carefully, the condition, how it works... I owe a lot to Doctor Marcela, I owe having a clean conscience to her!

However, looking at Ivan and the way he tells me the story, it doesn’t seem like he is totally at peace about not being at fault for his son’s condition. His concern now extends to his nephew Bruno, son of Elisabete’s sister who helped him come out of his depression. He had been diagnosed during the neonatal testing as a sickle cell trait carrier. “They told the

mother that he is going to lead a normal life, that either her husband or herself are also trait carriers and that that was never a problem for either of them. But I am scared, and she, the mother, is too. I am scared that it might turn into a leukaemia, something worse. At the end of the day, disease is disease, no one wants it close by, right?" Juliana – one of the geneticists that gives the monthly talks organised by the local Apae chapter to clear up doubts that parents of children diagnosed with sickle cell trait might have about the condition – confirms that Ivan's fears are quite common amongst parents. "Particularly the leukaemia thing, and it was even worse at the time that a soap opera had a female character with leukaemia who had to shave her head. At the time, in each and every talk we had someone raise the issue of sickle cell trait turning into leukaemia. We try to ward off people's worries, we give them all the information, but the talk lasts an hour, and the rest of the time it is those beliefs that reach them."

Ivan's fear regarding the disease is not only related to the condition itself, to the suffering it might inflict on the body, but also about the restrictions that pain and illness can bring to everyday life.

I think about that, I worry about Cauã, in the future, when I will no longer be here. See, I fall ill, I get the flu, I fight against the disease, I don't let the disease take over my life, you get it? I put up a fight, I get up, I don't give in. I might be burning with a fever, but I get up and go to work. Stay in bed? That's something rich people do, who recover in bed, waiting for the disease to go, letting the body rest. I put up a fight against illness. I stuff myself with medicines and keep on with life. But how about my boy, will he be able to do the same?

Ivan's worries are not unfounded, given that Salvador is consistently rated as Brazil's capital of unemployment and subemployment (Silva, Amon-Há, 2011). "What will be of my boy once I am gone?"

In Ivan's narrative, his son's condition not only maintained his already ongoing engagement with his care. Part of this care, from Ivan's point of view, is to make sure he follows all the medical recommendations not only with Cauã, but with his other son too. His concern about Cauã's future, the attention his partner and sister-in-law gave him during his episode of depression, and his deep involvement with the everyday chores which taking care of his sons involve are all part of the same "logic of care," according to Mol's (2008) term, in which he is enmeshed, in which family care is privileged and a lot of effort is devoted to maintaining these kinship connections.

The diagnosis of his son's sickle cell disease is incorporated, within this framework, into existing concerns and ideas about "care" held both by Ivan and other relatives before diagnosis. The attention and care given to each other's wellbeing within the kinship group, and the role biomedicine has in that care can only be properly understood if we take into account the effort made to maintain those relationships. Thus, biomedical notions about disease, health care and treatment get tangled up with other concerns and ideas about what is best for the family, including the need to provide a living and the yearning for the wellbeing of others.

Neonatal testing and family care networks

Dona Cleide is a robust middle-aged woman, who lives, like most of Salvador’s population, in a lower class neighbourhood in which irregularly self-built houses, with no access to sewage, and little to no access to public infrastructures is the norm. Every morning, at 5AM, *dona* Cleide walks up the unpaved road on which, after much effort she managed to build a three-room house, which still lacks rendering on the façade and interior walls, but with cemented flooring. After a 200 metre hike up the road, and two storeys of steps (given the road is so steep, if it wasn’t for the stairs access would be impossible), *dona* Cleide reaches one of the main avenues of the neighbourhood, where she will have to walk a further 500 metres to reach the bus stop. A trip on the local São Caetano/Pituba bus line, eight hours of work as a maid at two middle-class households, and a trip back, not to mention the time she has to wait for the bus to arrive, when *dona* Cleide gets back home it’s nearly nine o’clock. “But to me, I do it all to keep up with life’s struggle, you know, because they [she points at her three daughters], they mean everything to me, I want to give them everything I didn’t have, I don’t want them to experience what I did.”

While her mother goes up the hill, Tatiane, the oldest daughter, 17 years of age, wakes up Emily, 14, and after a bit of shouting, gets her to put on her school uniform and follow their mother’s path up the road towards the school where she is doing the last year of elementary school. Tatiane prepares breakfast for Laiane, her three-year old younger sister. After putting on her own uniform of the supermarket chain of US origin, known for its exploitative low salaries and long working hours, Tatiane gets Laiane’s backpack ready: powdered milk, two nappies, a baby’s bottle, a tub of dipirone painkiller and the dummy that Laiane, against her mother’s wishes, stubbornly refuses to give up. Tatiane then gets her own backpack ready, the uniform of the school she will attend after her shift at the supermarket, two school books, a notebook with the teen pop band in vogue, a lipstick, her wallet, and four reais for the bus fare. She won’t have money for a mid-day snack today, so she will just have to drink water and will tell colleagues that she is trying to watch her weight. Carrying Laiane, Tatiane goes up the same steps that *dona* Cleide and Emily did, towards her aunt’s house, her mother’s sister, who will take care of Laiane until Emily gets back from school, when she will be in charge of taking care of her sister until her mother gets back from work. “It’s a struggle, my kids were never very good at school, but the two of them are still at school, and they are going to complete their studies, oh yes, even if I have to insist, whatever it takes...”

Dona Cleide’s biggest concern, besides Laiane’s health, is that her three daughters will not have to depend on low-qualified jobs such as hers, to survive. Neither does she want them to depend on a man, even financially. Not least because, taking into account her own experience, and that of most of the women in her family, friends and even female neighbours, there is a high chance of the man not staying around for long, and, as happened with her ex-husbands, leave a few years into the relationship. With Laiane’s father it wasn’t even years, right after birth and sickle cell diagnosis he decided to travel to the city he was born and never come back to Salvador. The only contact Cleide has with him is limited to sporadic phone calls in which she asks him for help with the costs of taking care of their daughter. She is not sure if her daughter’s condition was one of the reasons that led him to leave home. And it doesn’t

really matter, given that the experience of abandonment isn't new for her, having happened after the two previous pregnancies: "That's the way men are, you can't change that."

Laiane's diagnosis of sickle cell disease during neonatal testing was not a complete surprise for *dona* Cleide. She knew for a while that an aunt of hers, who had already passed away, had the condition, even though she hid the fact from the rest of the family and blamed her bouts of pain on a badly cared form of rheumatism. "And you know how it is in the hinterland, you know, my city, it's very small, and we could hardly get a doctor's appointment, so everyone indeed believed that the problem lied with the doctor, who wasn't treating her rheumatism correctly." Later on, after Laiane's diagnosis, Cleide's older sister, who currently cares for Laiane while Cleide is at work, confessed that she too had sickle cell trait, which had been detected after she donated blood. She hid the fact from the family, fearing that they might think she had an incurable disease that could eventually cause her death. "She said she'd rather forget and not tell anyone, let God decide...she lives alone, she doesn't have anyone [is not married or has children], so she didn't want anyone to know so as not to worry us."

In the case of *dona* Cleide's two older daughters, who had not undergone neonatal testing, their paediatrician requested they were submitted to the haemoglobin electrophoresis test. The results showed that the two of them were sickle cell trait carriers. "I think for one the result was forty and the other 35 (haemoglobin S percentage), but I don't know, I don't know these things... let me see if I fetch the test results so you can have a look." Even if *dona* Cleide argues that she "doesn't know about these things", she has a remarkable memory of the haemoglobin S levels of her two older daughters: I check the numbers in the two pieces of paper with worn out corners that she hands me, forty and 35. Even when the paediatrician tried to reassure her that her two older daughters would not have any problems in the future "except avoiding establishing a relationship with someone with the same problem they have," *dona* Cleide cautiously keeps her two daughters' tests results, which she stores in a plastic file in which she also keeps other health test results of her two daughters. The file was stuffed with documents, as *dona* Cleide took pride in making sure her daughter had regular medical care.

The concern she had in keeping the test results is also related to the fact that, in spite of the paediatrician reassuring her about the effects of sickle cell trait, she still entertained the possibility that her older daughters might end up suffering from bouts of pain similar to the ones her younger daughter has. That is why, as far as the family income allows, she makes sure that her children receive a nutritious diet with plenty of vitamins. She also keeps hold of the test results as a reminder to them of the need to carefully choose their romantic partners. "As I say, it's hard enough as things are, a teenager, these days, a child nearly, she gets a boyfriend and soon enough gets pregnant. That's really common, and I don't want that for my daughters. Even more so because I know what it's like to take care of a sick child. That punishment, and I hope to God my children do not hear me saying this, I do not want that inflicted on my daughters." One of Cleide's neighbours told her that in order not to "pass on the disease," her daughters "shouldn't marry a black man." *Dona* Cleide had never heard that, the paediatrician had mentioned the need to test the partner before getting pregnant, or, as the paediatrician put it "start a relationship." But not marrying a black man?

See, my neighbour explained it all to me, she had studied it at school. During the time of slavery, the disease traces back to those times, when those who came [to Brazil] were darker, right? They brought [the condition], then it was white marrying black, and the disease was passed on. If they [daughters] don't want to keep passing the disease on, they should marry someone white, if they want to keep the heredity [of the disease], they can marry someone darker, that she [the neighbour] said that's the way it keeps being passed on...

Dona Cleide joins the dots between what the paediatrician said about the need to be careful regarding their daughter's relationships with the neighbour's discourse on the need to avoid “marrying” [a term used as a synonym of having children with] blacks, and goes on to argue that the disease is present in her family “because I have a grandmother who was black, really dark... it's hereditary, it's passed on.” However, Cleide also knows that with regards to matters of the heart, it is difficult to put rationality first. “I know that, when you are involved, passion speaks louder than anything else. Then it will be all down to God's wishes.” The geneticists that give the monthly informative talks on sickle cell trait at the Apae held a similar view. “When you like someone, do you think about anything else?” They also know that the “heart speaks louder” than a genetic test result.

Although dona Cleide's narrative has elements common to Ivan's story, such as the care given to keep track of all medical appointments and the emphasis placed on the need to maintain regular medical care for the family, there are some points in which the two stories diverge. Cleide's family arrangement, as the head of a female-only household, and the vulnerability this entails, has effects that can be thought through her narrative of engagement with the disease. Her concern with the impact that being a sickle cell trait carrier might have on her two older daughters' process of starting their own families, is not only related to their having to take care of a sick child. It is also related to their repeating the same experience of rejection and neglect from their partners that Cleide herself experienced after the birth of her daughters. She worries that they might repeat the relationship patterns she had in her life, and would like her daughters to have more stable relationships. Maybe her desiring that her daughters avoid giving birth to a child with sickle cell is the way she wants her daughters to constitute a life different from hers. At the same time, she is aware that her desire is just that, an aspiration. Her daughters' relationships, the stories they will outline in their own lives, will still be lived under the condition of being lower class women, with all the disadvantages that entails.

“Care” and the social body

– It was aimed at me, but she was the one affected

Fátima, 43 years old, chats with the mother of a child who also has sickle cell disease. They are both waiting for a doctor's appointment for their children at the local hospital that provides specialized haematological treatment for the condition. After being asked about the story of the diagnosis of her eight-year-old daughter Isadora, Fátima argues that her daughters' disease was caused by an Afro-Brazilian spell (*macumba*). Supposedly ordered by

her husband's mistress with the intention of splitting them up. Fátima believes that due to her spiritual strength, the spell didn't affect her. Given that she was pregnant at the time, however, the spell did affect her unborn daughter.

You know, I knew he was with another woman, yes, I did. But what could I do? Forego having a man? Do like I did when I separated from my other husband, that I had to pretend in front of neighbours that he still lived with me? I used to ask my children [two sons from that marriage] not to let anyone know that he was gone and that we were leaving alone. And yet some [neighbours] heard he had left and then there were men at the gate, asking about me, where is your mother, go get her and tell her I want to talk to her... as if I was an easy woman. So, what were my options, when I knew that my husband had another woman? To put up with it, my dear, to bear it.

In spite of arguing that she "put up with it," Fátima did confront verbally several times her husband's alleged mistress, who lived in the same street as they did.

I quarrelled with her plenty of times. I could feel my blood pressure go up, I held onto all my anger, you know. And I would scream at her, call her bitch, slut, all of that in the middle of the street, so that everyone knew what she was doing. And I think that's why she got someone to cast the spell, she had it done, so that I got sick, because she was angry with me. What she didn't know is that I am spiritually protected from all that evil doing. But, in turn, she was affected [points at her daughter], so she got that problem with her blood. It wasn't aimed at her, it was for me, and it wasn't disease, it was really meant to kill me. She wanted me to die, so that she could be with my husband for good.

Fátima doesn't think her daughter's condition is the result of a hereditary genetic condition. As a proof of the impossibility of the disease being hereditary, she mentions the fact that neither her haemoglobin electrophoresis nor her husband's had come back with abnormal results. "It was a spell, it was indeed."

The woman she is chatting to in the waiting room, Locádia, 31 years of age and mother to a ten-year-old child who has only been recently diagnosed with sickle cell disease, in spite of initially trying to question Fátima's explanation for her daughter's disease, ends up conceding that in that case, "it can indeed be the work of the forces of Evil." A regular at the God's Assembly Church in the city of Simões Filho, outskirts of Salvador, Locádia recommends Fátima to take her daughter to church, where she will be able to obtain help. "I have been to church, been to *terreiros* (Afro-Brazilian Candomblé temples), I have gone everywhere. But they all say the same thing, that we have to bear the situation, be strong, because this problem [the disease], she is going to have for life, it's lifelong." Locádia nods, but she insists: "you have to remain faithful to God, only God gives us the strength we need."

However, the fact that Fátima doesn't accept, in the case of her daughter Isadora, biomedicine's etiological model that classifies sickle cell disease as a recessive genetic hereditary condition, and believes that it has a religious cause, doesn't mean that she wholly rejects the biomedical model of treatment. Thus, she never stopped taking Isadora to hospital to receive treatment, nor stopped diligently giving her the medicines the doctors prescribed.

At home we have a box I set aside for this purpose, with all her medicines. I write down the timings [she has to take medicines] in the box's lid and I leave it on top of the kitchen table. No one [her other children or husband] is allowed to touch the box,

I don't let anyone mess with it, only I give her the medicines, I force her, there are days when she doesn't want to take them, but I force her, I tell her she needs the medicines to be strong and be able to play.

Fátima has also incorporated some of biomedicine's knowledge regarding the effects the disease has on her daughter's body, showing familiarity, as I found amongst a lot of parents of children with sickle cell disease, with medical terms. Concepts such as “basal haemoglobin levels” feature frequently in parents' conversations, who also incorporate other medical knowledge such as the ways to detect an enlarged spleen, which might indicate splenic sequestration, requiring urgent medical care. “I always keep an eye on her, checking her side, and taking her to the doctor. I give her the medicines; I do all that. But, regarding that issue [the religious origin of her daughter's disease] I leave it alone, right now, all is left is to accept how things are.”

As in the case of Ivan and dona Cleide's stories, Fatima's narratives points at how “following medical advice” is central to the ideas about “care” found amongst families with children diagnosed with sickle cell. Giving the medicines at the right times, being in charge of their child's medical treatment, taking care of symptoms, being attentive towards any change in their children's bodies, knowing when to resort to urgent medical care, are all attitudes that are present not only in the everyday life of Fátima and her daughter, but also in the other stories I deal with in this article. Common to them is the incorporation of biomedical knowledge to the everyday care given to these children. At the same time, Fátima's narrative emphasizes how that incorporation does not preclude rejecting other explanatory models for sickle cell disease or other conditions and bodily processes. To be able to reflect on the ways in which biomedical technology features in people's everyday lives and how the decisions regarding caring for the disease are taken, we need to understand how that care is interrelated to other life experiences. These experiences are permeated with issues regarding, for example, power relations related to gender relation dynamics and the socioeconomic context in which people live.

“A mission in life”

Renata is in the hospital waiting room. She looks towards the child sitting in a woman's lap next to her and, without even asking the reason for their being there, she smiles and strokes the child's hair “Sickle cell disease?” The mother nods. “My two boys have it too, I know what it's like.” And she does indeed know. She knows in a very intimate way, not only by being a mother to two children with the condition, but also due to the story of her second pregnancy. During her first pregnancy, Renata, in common with other first time mothers, was really nervous. A new universe, new plans, anxiety, fears, new possibilities too. With her son's birth and later diagnosis came the story of being involved with caring for the disease: going from specialist to specialist, appointments with different doctors, managing bouts of pain, a blood transfusion here and there, fear, sadness, concern. Her engagement with the disease also affected her marriage: her then husband decided that he would not be able to cope with the situation and preferred to separate from her. Renata faced the challenge of taking care of her child, at the time with 3 years of age, alone. With a full-time permanent

contract as clerical support staff at the local Town Hall, Renata could count on a steady income that allowed her, alongside the child support she received from her ex-husband, to have a relatively comfortable life. Without luxury, but without wanting for anything. An apartment in a council block on the outskirts of Salvador, holidays at her mother's house in the state countryside, clothes bought on credit cards. Even a neighbourhood private school for her son she could afford. But Renata missed having someone to talk to when she returned home from work. She missed putting her child to sleep and then sharing with a partner the remains of the day. Winter time? That's when Renata really missed a male body to which she could hold onto tight and hear the rain falling. But she was having difficulties finding that certain someone. Until one day a friend introduced her to Ronaldo, who also worked for the local municipal government. Ronaldo was tall and handsome, with an easy smile. He won her heart on the first couple of dates, which turned into a serious relationship after six months, mediated by an engagement ring.

They planned their wedding for a long time, a wedding that only took place once Renata convinced Ronaldo to marry at Church. This was not due to their being devout Catholics, but rather to please their families, particularly Ronaldo's mother, who was already quite old. But if Ronaldo didn't hold the dream of having a Church wedding, he had longed to become a parent for a long time. He was warm and attentive towards Renata's son, but he always talked about their future child. He even picked a name for him. "Marcos is going to love football, you'll see, I'm going to take him to the Fonte Nova [local football stadium], he's going to be crazy about Bahia [local football team]." Renata smiled and nodded. Of course she wanted to have another child, who wouldn't want to have a child with a man like Ronaldo? But she also knew that before getting pregnant, they would have to get Ronaldo's test to see if he was also a sickle cell trait carrier. They made an appointment with a haematologist, who explained the whole test and the chance, in case it was positive, of their having a child with the condition. Renata was already familiar with all this information, information she had received during the diagnosis of her first child.

The day Ronaldo went to get the blood drawn for the test, Renata woke up worried. She had dreamt that his test was positive. Ten days later, Ronaldo came back from the laboratory with a sad expression and a test result that confirmed that he was also a sickle cell trait carrier. Renata phoned one of the geneticists who had been involved in her first child's diagnosis and arranged an informal appointment with Ronaldo and herself. The geneticist explained once again that the condition was genetic, and that given that both were trait carriers implied that every pregnancy they had a one in four chance of having a child with the disease. The chat with the geneticist seemed to cheer Ronaldo up. "Darling, our son is going to be beautiful." Renata wasn't totally convinced, it was hard for her to forget the experience of her first pregnancy and how the marriage ended. "But I could see he really wanted to father a child. He would not stop talking about Marcos, Marcos is going to be this and that, all the time." So in spite of her concerns, Renata got pregnant four months after the chat with the geneticist. "I got pregnant, with some fears, but Ronaldo didn't speak about the disease not even once during the pregnancy. It was a marvellous pregnancy, I had never been treated like that, with so much care!" A baby boy was born, Marcos, as his father wished. And the neonatal test confirmed that, once again, Renata would be the mother of a child with sickle

cell disease. “But Ronaldo, well, my love for him just grew and grew, actually, the love we have for each other, it grew. Because everything he wanted was to become a father, he knew about the disease, by had witnessed how things were with my other son, he knew how the treatment was, the everyday life. So it was nothing new for him. And he was so happy, ecstatic with Marcos, I saw him fulfilled.” In fact, Marcos’ birth seemed to bring Renata and Ronaldo even closer, and they plan another pregnancy in the near future. “A baby girl, Caroline, to give my boys a sister and to stop being a minority in my own house!” If she also has sickle cell disease, then it would just confirm what Renata thinks: “Sometimes I think my mission in life is to take care of children with sickle cell disease.”

Final considerations

I chose to end the article with Renata’s story, given the unexpected involvement of diagnostic technology in crafting a meaningful life. Her story shows that separating analytically “technology” from “life” does not contribute to our understanding of situations such as those she had to face in her second, current marriage. Understanding the story of Renata’s involvement with sickle cell also illustrates, in a very incisive way Mol’s argument for the need to confront the “logic of care” with the “logic of choice” in which the citizen, by exercising his choice, would be enacting his citizenship.

Thus, Renata and Ronaldo’s choice to get pregnant cannot be simply understood in terms of the “logic of choice”, in their having calculated the risk they had in having another baby with sickle cell disease, evaluating in an objective way the information biomedicine was presenting them with. Renata and Ronaldo’s visit to the geneticist, as told by Renata herself, did not influence the plans they had for becoming parents, confirming Mol’s argument (2008) on the need to stop considering absence of disease as the standard for normal humanity. In a similar fashion to what feminism does by questioning masculinity as equal to being human, going against the view that situates femaleness as deviant from that standard, Mol provocatively defends the need to develop a “patientism,” which would question the absence of disease as the pattern for normal, both in terms of citizenship and humanity itself (Mignolo, 2006).

In that sense, the four stories presented in this article help us think the disease not necessarily as a break in the normal flow of life. An example of this is the maintenance of conjugal ties after receiving the diagnosis of sickle cell in one of the couple’s children. Relationships that abruptly end, allocating childcare to women with absent fathers, are all common experiences in relationship dynamics, and certainly not exclusive to those couples who have born children with sickle cell disease or any other medical condition for that matter. However, this is not the same as arguing that the experience of having a child with a certain disease does not have an impact on the relationship dynamics of couples. Rather we argue that this impact is set within wider life experiences and not limited to the disease itself.

The effect that diagnosis and care of sick children can have on conjugal relationships can be included within the wider life project of both men and women. In the case of dona Cleide, the detection of sickle cell reinforced a pattern of breakage of affective links she had already experienced in previous relationships, an experience she had in common with other women in her social circles. For Fátima, the very understanding of the aetiology of the disease

is set within what she understands to be the dynamics of relationships between women and men. The troubled relationship she had with her partner and the “competition” between women over men makes Fátima accept certain situations she identifies as humiliating, and yet also part of “normalcy” of living with a man. Renata, in turn, experienced the end of her first marriage as being very closely related to her devotion towards her newborn after his sickle cell diagnosis. Even when she reports that she gave a lot of attention and time to her child’s care due to its diagnosis, we cannot exclude outright the possibility that she might have devoted equal time had he not been diagnosed with the condition. We should also bear in mind that she is speaking about this phase of her life after establishing a new relationship and undergoing another pregnancy with her new partner in which she was fully supported by him.

In that sense, in Renata’s current marriage, as is the case of Ivan’s, we can identify a certain project for the family unit that has several characteristics in common: their narratives do not underline conflict as being central in their relationships, on the contrary, collaboration and companionship are emphasized, with the stories of sickle cell diagnosis of their children set within this pattern of mutual care between partners. There is, however, a difference between Ivan and Renata’s stories. In the case of Ivan’s, his child’s condition brings with it some concern about his future livelihood. This concern is not only related to the financial situation of Ivan, who cannot fully support economically his family, depending on his wife’s salary to cover the household’s expenses, but also on his idea of what a man’s role within the family is: providing for his offspring materially and giving them the resources to eventually provide for themselves and their own families, reproducing the family model.

Cleide, in turn, desires the social betterment and emotional stability for her daughters that she couldn’t attain for herself in her own life, her biggest wish being that her daughters do not repeat her position within the job market nor reproduce the kind of romantic relationships she had. The ways in which experiences with the disease are set within existing family dynamics influenced in turn by the intersection of gender/class is, in fact, a feature of all the stories presented in this article. In that sense, Renata’s narrative brings another possibility: the disease being central in the life and family project she constitutes in spite of, and thanks to, the disease itself. Her socioeconomic situation, more financially stable than the rest of the families of the other narratives, might have an influence in the “caring” for the disease being turned into a positive life project. Another question to factor in is the experience of his second child’s diagnosis not taking them by surprise. Either way, Renata’s story exemplifies how the notion of “care” itself can give meaning to the life of those involved with diagnostic technologies and its effects, going beyond Rabinow’s (1992) idea of biosociality, which, at first sight, might explain Renata and Ronaldo’s behaviour while planning their pregnancy and later on with their child’s diagnosis. The stories of Ivan, Cleide, Fátima and Renata illustrate that the insertion of the diagnostic technology of neonatal testing within already existing networks of “care” or created after diagnosis, can become part of the fundamental flows of life, without necessarily becoming what guides it. The lives narrated here are permeated by their protagonists involvement with neonatal testing and other medical technologies, set within an everyday context of practices of care that, in spite of including their experiences with biomedicine, go beyond it.

NOTES

¹ Another quality cherished by neoliberalism, “flexibility” was pointed by Emily Martin (1994) as a central element in this new logic of biomedicine.

² An interesting discussion that is outside of the scope of this article is the different notions of citizenship in their local, not necessarily Western, contexts.

³ Within this context of providing possible alternatives to the “logic of force” we could situate, for example, Brazil’s National Policy for Humanizing Medical Attention (Política Nacional de Humanização da Atenção e Gestão no Sistema Único de Saúde, HumanizaSUS), led by the Ministry of Health. The aim of this policy is not to promote the idea of individual choice, but rather the “production of a sense of collective that sustains collaborative constructions... [with the intention of] producing a new kind of interaction between the subjects that constitute health systems and which use them, welcoming such actors and promoting their protagonism.” This policy is set between a “logic of choice” (although based on ideas on the collective and not necessarily on the individual), and the “logic of care.” See Brasil (s.d.).

⁴ Resolution n.196/96 of National Health Council (Conselho Nacional de Saúde, CNS), that deals with research with human beings was met. Data collection started after the projects’ approval, elaborated according to guidelines set by the local ethics committee to which the participating institution was filiated. The names used to identify informants are not their real names.

⁵ Personal communication, 18 jul. 2015 by Ana Stela Goldbeck, PNTN, General Coordination of Blood and Hemoderivates, Ministry of Health (PNTN, Coordenação Geral de Sangue e Hemoderivados, Ministério da Saúde).

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