

Experience of people living with the Berardinelli-Seip Syndrome in the Brazilian Northeast

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Abstract *This paper analyzes the experience of people living with the Berardinelli-Seip Syndrome in the Brazilian Northeast. This qualitative study was developed with eleven informants, namely, nine people living with the syndrome and two mothers. Information was gathered using participant observation, social characterization and semi-structured interviews. Data were analyzed by means of a thematic coding technique. Two categories emerged: (1) 'the secret is to shut your mouth': food management in daily life; and (2) 'Ah, is it a transvestite?' body, gender, and masculinization. We concluded that, in the experience of the informants, their negotiations and creativity translated into strategies for food management that integrated tastes, values, habits, biomedical prescriptions and pleasures involved in commensality situations. Regarding corporeality, it has been shown that representations and experiences with the body show gender inequalities, insofar as women become privileged targets of stigmas, prejudices and discrimination in adult life.*

Key words *Congenital Generalized Lipodystrophy, Medical anthropology, Illness experience, Food, Gender and health*

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Introduction

In Brazil, socio-anthropological studies on long-term illness and suffering (chronic disease, in the technical language of biomedicine) currently show an important accumulation of research and cover a variety of conditions¹⁻³. A particular interest in long-term illness and suffering has recently emerged in the field, the etiology of which is genetic and incidence and prevalence rates are low, which includes them in the list of rare diseases, according to clinical and epidemiological parameters.

Literature points to a variety of terminologies for these types of illness and suffering, with special emphasis on rare diseases and orphan diseases. Regarding the definition, these are modified depending on agencies and countries. Richter *et al.*⁴ proposed in their systematic review that the term “rare disease” is the most realistic and covers those whose global prevalence threshold ranges from 40 to 50 cases/100,000 people. According to the Brazilian Ministry of Health, there are an estimated six to eight thousand different types of rare diseases, 80% of which are due to genetic factors and the others related to environmental, infectious and immunological causes, among others⁵. In descriptive terms, such association with genetic factors is not corroborated by the literature⁴.

From this perspective, this paper joins other intellectual initiatives in the field of socio-anthropological studies on rare diseases and genetic etiology. It is assumed that the “new genetics” facilitated not only the description and identification of individual genes, but, above all, predictions about their future and the future of their relatives in terms of health conditions, based on the genetic risk estimate^{6,7}. Thus, application of genetic knowledge in clinical medicine has made it possible to redefine “what is health, disease and debilitation in an essentialist and biologically determined way”⁸. In addition, the explanatory category “gene” gained strength in scientific and popular discourse, since it became a symbol and a metaphor and made it possible to reexamine the boundaries between normal and pathological⁶. Unlike studies that address topics more closely related to the effects of geneticization on social life through ethnographies over notions such as genetic inheritance and predictive tests^{9,10}, this paper focuses on the experience of people living with this type of disease, specifically with the Berardinelli-Seip Syndrome (BSS) in the Brazilian Northeast.

BSS is a rare genetic disorder whose inheritance pattern is autosomal recessive and characterized by lipodystrophy that causes complete atrophy of subcutaneous adipose tissue and extreme insulin resistance¹¹. It was first described in 1954 by the Brazilian physician Waldemar Berardinelli in a two-year-old boy¹² and reviewed in 1959 by the Norwegian M. Seip from three patients, two of whom were siblings with the same clinical characteristics¹³.

Since the earliest cases in the 1950s, approximately 300 to 500 people diagnosed with BSS of various ethnic origins have been reported in the literature, highlighting the populations of Brazil, Portugal, Norway, Scandinavia, and Lebanon¹⁴. Notwithstanding this, it is believed that cases are underreported, presuming that only 25% of people are diagnosed, so the exact population prevalence of BSS is unknown, estimated at around 1:10,000,000¹⁴. In Brazil, the highest prevalence of BSS is recorded in the state of Rio Grande do Norte, Northeast of Brazil, with a ratio of 1:128,000¹⁵. Studies on the genealogy of the families that colonized this region have attributed the high prevalence of BSS to Portuguese origin¹⁶. Such historical evidence has been corroborated with biomedical research, since there are descriptions of gene mutations among individuals of Portuguese origin¹⁷.

Clinically, BSS is commonly diagnosed at or shortly after birth, due to the phenotypic pattern of the newborn with marked presence of muscle hypertrophy and complete lack of subcutaneous adipose tissue¹⁸. In addition, the course of the disease is marked by a series of metabolic and systemic alterations, especially diabetes mellitus, systemic arterial hypertension, hepatic steatosis, dyslipidemia and renal failure¹⁹. The clinical management of BSS consists of strategies to cope with its metabolic complications, and diet management is the most important aspect in biological effects control¹⁷, as well as stimulating the practice of physical activities. Dietary guidelines include restriction of total energy intake, saturated fat and simple carbohydrates, giving preference to the consumption of complex carbohydrates, soluble fibers, medium-chain triglycerides and unsaturated fatty acids²⁰. The treatment also consists in the use of drug therapy, mainly insulin and oral hypoglycemic agents. New treatment modalities have shown promising results according to physicians, with emphasis on therapy with the replacement of recombinant human leptin²¹.

A vast production with genetic, molecular and clinical analyses was evidenced¹¹ In the spe-

cialized BSS literature. In Brazil, there are some case reports with clinical and genetic descriptions of individuals living with BSS^{19,22,23}. As far as socio-anthropological literature is concerned, no studies were found in the international or national databases. Thus, this paper analyzes the experience of people living with BSS in the Brazilian Northeast. It is important to say that studies of this nature give voice to people, insofar as they express, interpret and communicate their experiences of distress and actions to manage the disease in daily life.

Methodology

The theoretical framework adopted in this study is the experience with long-term illness and suffering in the socio-anthropological perspective. The studies produced in this theoretical current aim to stress the physicalistic perspective with which biomedical knowledge holders have been committed. They do this insofar as they bring to the debate the different forms of experiences with the illness and suffering of real people, through integrated, relational and holistic analyses²⁴. Therefore, it is assumed that studying the experience of people with a specific long-term illness or suffering means addressing, from a theoretical and empirical point of view, aspects of individual/private life and, at the same time, of collective/social life^{1,25,26}.

In this investigation, we worked with the understanding that experience with long-term illness refers to the ways in which people and their social support networks, in socio-historical contexts and specific biographical situations, express, interpret and communicate the (inter) subjective and objective place, as well as the effects of the illness on the self and on the daily construction of its project of being in the world^{1-3,24,25,27}. This place is composed and traversed by a set of events (diagnosis, crisis, medical interventions, etc.), relationships (family, school, work, doctor-patient relationship, etc.), social markers of the difference (gender, race, ethnicity, generation, sexual orientation, etc.) and diverse care practices, since they integrate medical and popular technologies. All of this is mediated by meanings, definitions, and interpretations built intersubjectively – hence, socially and culturally, which produce (or not) actions to create, reorganize or maintain and manage their way of life^{2,27,28}.

From the methodological viewpoint, this is a qualitative research, since it has worked with the

human being in society, its relations and institutions, its history and its symbolic production through narratives limited locally, time wise and situationally²⁹. The fieldwork took place between November 2015 and December 2016 and involved meetings with the interlocutors and participation in various social situations in the municipalities of Currais Novos, Caicó, Carnaúba dos Dantas and Natal, in Rio Grande do Norte and Picuí, in Paraíba. During this period, two Annual Meetings of the Association of Parents and People with the Berardinelli-Seip Syndrome of Rio Grande do Norte (ASPOBERN) participated. These events gather people living with BSS, their families and health professionals (physicians, nutritionists and physiotherapists linked to a Federal Institution of Higher Education – IFES, which list will be discussed below). In these social situations, participants' observations were made, whose descriptions were recorded in field diaries.

With contacts and links established inside and outside the Annual Meetings, individual interviews were held, involving the visit of the research team to the households of the interlocutors. This process evidenced two difficulties: 1) travel logistics; and 2) access to the interlocutors was hampered due to the linkage of these subjects to researchers with a biomedical matrix that guides their participation in other research. To mitigate the latter, we mainly relied on the support of one of ASPOBERN founders.

The study was developed with nine people living with BSS over 18 years of age, and two mothers. The sample was intentional and based on the “snowball” strategy, totaling 11 interlocutors. After initial contact at the ASPOBERN event, invitations to participate in the survey were made by telephone and, after being accepted, the interview was scheduled at the interlocutors' address at the time of their choice. The research team's traveled in official university vehicles.

Three procedures were used to collect data: participant observation, social characterization and semi-structured individual interviews. Informants' characterization data were collected through a structured sociodemographic questionnaire. Interviews aimed to apprehend the peculiarities of experiences of people living with BSS. In total, 11 interviews were carried out. Each interview was done by only one researcher. The mean length of interviews was 90 minutes. The script with semi-structured guiding topics was previously tested and subsequently used in individual interviews.

Data review occurred concomitantly with the collection. Initially, a brief description was provided with information about the people interviewed, the interview context and the identification of the central topics. Interviews were transcribed and analyzed using the thematic coding technique²⁹. Thus, we proceeded to the open coding and then selection for the production of a system of categories that encompassed the concepts and codes found in the statements of respondents. Finally, the items and variations in the categories found were analyzed with a view to assigning them meaning and establishing the relevance of variations and categories themselves for the general case.

The Research Ethics Committee of FACISA/UFRN approved the project. Interlocutors signed the Informed Consent Form (ICF) and are identified in the text by means of fictitious names randomly chosen by authors.

The experience of living with the Berardinelli-Seip Syndrome

After analysis and interpretation of the empirical material, two thematic categories were obtained: “the secret is to shut your mouth”: food management in daily life; and “Ah, is it a transvestite?” Body, gender and masculinization. By convention, single quotation marks were used to highlight emic terms and expressions. The contents of each of them is shown below.

‘The secret is to shut your mouth’: Food management in daily life

From the biomedical viewpoint, BSS is a disease whose management implies strict dietary control. Thus, this category highlights the centrality of food management in the control of BSS-associated comorbidities and in the experience with the disease. In this process, self-monitoring, self-control of ‘excesses’ and management of eating practices in daily life are emphasized.

In the empirical material of the study, the prescriptions of diets and dietary restrictions are listed as central elements to avoid BSS complications. This implies the development of self-technologies (self-control, self-discipline and self-monitoring) in order to keep “rates” within parameters set by biomedicine. Such an emphasis was explicit, for example, in the words of Antônia (mother and founding partner of ASPOSBERN) given at the Association’s Annual Meeting in 2015: “*I wish to thank everyone for be-*

ing here and wish them a happy Christmas and a prosperous new year. I hope that everyone will have their rates controlled at our next meeting” (Field diary, 28/11/2015).

In this context, “rates” expressed in laboratory tests give visibility to what doctors and nutritionists cannot see: daily dietary practices. Thus, the examination combines “the exercise of monitoring, the application of normalizing judgment and the material inscription technique in order to produce quantifiable individuality traits”³⁰. Examination and perennial evaluation of “rates” in the experience of people living with long-term illness produces a “grammar of numbers”³¹ which, through practices such as ‘*measuring*’, ‘*seeing*’ or ‘*removing*’, allows individuals to build lifelong disease-centered self-awareness. Socio-anthropological studies with people living with diabetes accentuate the panoptic effect exerted by laboratory tests^{32,33}.

From this economy of visibility introduced by laboratory examinations³³ and its “grammar of numbers”³¹, the experience of the interlocutors with BSS is marked by self-monitoring practices that must be observed in all walks of social life, especially in commensal situations. According to interlocutors, these self-monitoring practices go through their daily activities, as Marcelo (29 years old, white, Catholic, heterosexual, engaged, higher education completed, resident of Natal with the family, employed, at the time of the fieldwork was the President of ASPOSBERN) said: *the difficulty is to shut my mouth. Just that. Because it is not easy for people to give up food.* This ‘*difficulty*’ gains expression before the Sertanejo’s typical cuisine of the region of Seridó – where nine interlocutors lived.

The Seridó Mesoregion consists of 54 municipalities in the states of Rio Grande do Norte and Paraíba and is characterized by scarce and unsteady rainfall, high temperatures and low humidity. Historically, the region has been marked by droughts, which leads to environmental and climatic vulnerability and unsustainable economy. In contrast, the region has a cultural, material and immaterial heritage, constantly updated by natives. These last ones have such a marked cultural and regional identity that, according to one of the interlocutors in an informal conversation, *The Seridó native is to Rio Grande do Norte what the gaucho is to Brazil.* He said this to emphasize that in his analysis, the first identity (Seridó native and Gaucho) overlaps with the second.

In Seridó, traditional “food” is characterized by milk-derived ingredients (rennet cheese, but-

ter cheese, cream, “earth butter”), strong seasoning, sweets and beef consumption, especially sun-dried meat. During interviews at respondents’ households, researchers were frequently invited to join in meals, especially at lunch. On these occasions, it was observed that lunch included food common to the menu of most of Seridó’s native families³⁴. In other words, the food culture opposes dietary restrictions and prescriptions for people living with BSS who, in the words of Paula (21 years, white, Catholic, heterosexual, single and no boyfriend, high school completed, residing in Picuí-PB with the family, unemployed), should be: *A healthy diet. Eat diet and whole food, avoid fat and dough. Eat more vegetables*. This context increasingly requires people living with BSS to produce management strategies, given the meanings of food and eating habits in the Sertanejo’s culture³⁴.

Thus, commensality situations are spaces where the practice of moderation and avoidance implies limitations and difficulties that can influence the social relationships of individuals. As reported by Marcelo and Luiza, when going out with friends, keeping food restrictions is a must: *all my friends know that I cannot eat anything greasy, with sugar, nor drink or smoke. This is when I need to be careful because this is where it starts. You go out and a friend offers you something: ‘Come on, have some, it will not hurt you’ (Marcelo). You will sometimes go out with your friends and have to change plans because there is nothing you can eat where you are headed. Because they like you and do not want to disappoint you, they change the program (Luiza, 19, white, evangelical, heterosexual, single and no boyfriend, high school completed, resides in Brejo do Cruz-PB with family, student of pre-university preparatory course).*

Then, Daniel (25 years-old, white, Catholic, heterosexual, single and no girlfriend, higher education, residing in Caicó-RN with his family, teacher of the state school system) explains that he needs to be *very conscientious and mature. You have to keep an eye on yourself!* Therefore, people can be considered as being or not ‘conscientious’: *being unaware means knowing you cannot, but being carried away by impulse and ending up eating, undoing treatment and dietary guidelines. On the other hand, the conscientious person knows that it has to follow it strictly, even if it is bad. It’s about being responsible and knowing what you have to do because it’s for its own good (Luiza).* In both cases, individuals are responsible for their own health, which can be understood as an increased individualism on health care relationships³⁵.

This process of accountability of people living with BSS takes on broader lines given the relationship between ASPOSBERN members and a group of professors and researchers from an IFES in Rio Grande do Norte. In 1987, Leila (mother and founding partner of ASPOSBERN) and Antônia met these teachers and researchers on BSS on the occasion of the diagnosis of their children, and thus, enabled access to medical professionals, especially endocrinologists and geneticists and to treatment. In parallel, the group of researchers began to develop research in genetics, biochemistry, nutrition and endocrinology in order to qualify the health care of these people. According to our interlocutors, this relationship provides beneficial results for all: scientific publications, for the former; and medical care and care with professionals who are well versed in BSS, for the latter. The relationships of power-knowledge found there and their implications in daily care practices, in the conditions of production of scientific knowledge, in social medicalization and in the biopolitical management of the lives of these people are highlighted.

In this relational context, the category ‘consciousness’ can be interpreted as ‘being responsible’ for using and applying biomedical knowledge in a balanced way with own food tastes and desires in daily commensal situations. The assimilation and reinterpretation of this knowledge enables a greater arsenal of management strategies. In addition, being ‘aware’ implies self-discipline, self-control, self-monitoring, ‘not getting carried away by impulse’. In the experience of our interlocutors, ‘consciousness’ overlaps the ‘control’ category, and the latter is a consequence of the former. This fact demarcates a setting of discursive disputes between scientific knowledge and popular knowledge. Unlike results from other studies with long-term illnesses that associate disease management with the notion of control^{32,36,37}, in the experience with BSS, such association occurs with the category of ‘conscience’.

In the face of these self-technologies, subjects develop their own creative strategies for living with illness, as Daniel reported: *I knew since I was very young that I had the syndrome, but this does not mean that I complied exactly with the diet. I ate less, but I did not avoid it altogether. One thing is you knowing, another thing is what actually happens... Actually, as he said, diet and food management includes being ‘conscious’ that, if on the one hand, it can generate adherence and obedience, on the other, it enables the production of diverse negotiations that hybridize, to some extent, medical*

and nutritional guidelines with the taste and pleasure of eating. Sometimes I just bend the rule a little [regarding the diet]. Nevertheless, I am aware: I am afraid of getting sick. I know how far I can go. I eat, but the next day I try to run, do something to burn the fat (Marcelo). Daniel says: I'm not saying that I am not eating pasta. I eat in moderation, also because everyone needs carbohydrates, glucose and vitamins. It's all about quantity.

As in the experience of people living with hypertension²⁶ and diabetes³⁶, the interlocutors of this study emphasize differences in diet and food management according to the days of the week. These weekly schemes of moderation and avoidance practices are also reported in other studies and imply that they do not exaggerate or exceed the quantity and types of food and beverages on weekdays²⁶ and, on weekends, holidays and festivities, excesses and pleasures of eating and drinking are more loose, suspending or relaxing food restrictions³⁶. *I do the same diet on weekdays: I don't eat sweet, fried and such things... Mango, jackfruit, here and there, because they contain a lot of sugar. When I have a weekend, I bend the rules a little! I always eat a piece of cake and other things I should not eat* (Kay, 27, white, Catholic, heterosexual, single and no boyfriend, higher education completed, resides in Currais Novos-RN with family, unemployed).

It is important to emphasize that even when interlocutors are adolescents or adults, protective care is provided by doctors, family members and ASPOBERN members. An example of this is the availability of a WhatsApp social network group in which IFES-affiliated doctors, people living with BSS and their families participate. These are, therefore, control strategies that interconnect in the daily life of these people.

'Ah, is it a transvestite?'

Body, gender and masculinization

The most relevant aspect of this category concerns the gender discrepancies faced in the BSS bodily experience, evidenced by the point of view of interlocutors. Body marks imprinted by the 'skinny gene' that causes BSS characterize people who live with this syndrome as muscular and manly, which becomes a problem in women's body experience, often marked by stigma and rejection. It is important to describe the representations and social imaginaries that involve the body of the person living with BSS in the context studied.

According to the oral tradition of the region, the *people of the Magi* have a lean, muscular body,

with *bulging veins, big belly*, without *cheekbones* and with voracious appetite as children. In the field of human sciences, a pioneering study¹⁶ revealed some elements of the social imaginary in relation to the '*people of the Magi*': malnourished children, ill-treated children, children mixed-up in the hospital (since they did not look like anyone in the family) children born with lots of bones, girls with boys' sex (inscribes the gender marker in the experience of these people), people who appeared to be older – aging faces.

These bodily marks circumscribed a strange person, an abject and ambiguous, but not necessarily diseased body in the biomedical sense. The popular denomination 'disease of the Magi' inscribed an abnormality, whose biomedical causes and classifications were difficult or impossible to determine. 'Disease' here can be understood as a situation of deviation from the norm, a different³⁸ (and unknown) way of 'enjoying'. It should be noted that, until 1987, there were no cases in the region with an accurate medical diagnosis. Thus, the 'Magi' were (or still are) incorporated as a possible "character" in those places, therefore assimilated, in their strangeness in the daily life of cities. Thus, experiences of discrimination related to BSS' body marks that have gained more prominence have emerged in the narratives of women's experiences.

I've received criticisms and jokes like 'Ah! Are you on steroids?' or 'Look, it looks like a man! What is it: is it a transvestite?' These comments occur because most people do not know the syndrome, they criticize us and stare at us with that estranged look in their faces (Kay). Thus, the body of a woman living with BSS challenges the hegemonic pattern imposed by heteronormativity, where sex and gender must coincide.

Unlike transvestites for whom sex and gender do not coincide with the social pattern, leading to a series of bodily transformations (hormonalization, for example)³⁹, in the experience of the woman living with BSS, the lean, muscular body, with *bulging veins, big belly*, without *cheekbones* is what does not fit the norm. These issues may make BSS *burdensome to women*, as Daniel suggested.

This *burden* translates into stigma, prejudice and discrimination, as reported: *every year we spend our summer vacation in Pirangi [beach of the southern coast of Rio Grande do Norte]. Once I went to take a bath and when I got out, a couple stopped me and the woman asked: 'Are you on steroids?'. Then I started laughing and said, 'No, I am not. Why?' She said: 'It's because you're so muscular. Your physique looks like those people are*

on steroids, do a lot of bodybuilding, and the veins show up'. Then they looked at me from head to toe and said, 'Okay, I'm sorry' (Kay).

Women's muscular body is also reported in the experience of female athletes as "a field of definition and redefinitions of meanings about the female body, femininity and being a woman"⁴⁰. According to Adelman's study⁴⁰, despite showing that fitness reconciles with femininity as a repository of normativity and reformulating certain ideas about the female body, its forms and its capacity, these women do not break with highly normative masculine and feminine definitions; they do not give up a whole self-monitoring system required to sustain femininity.

Kelly (34 years, white, Catholic, heterosexual, single and no boyfriend, incomplete elementary school, resided in Carnaúba dos Dantas-RN with the family and received a social security benefit. She died two months after the interview due to BSS comorbidities complications) reported in a low voice: *once I was at the square and a boy started to stare at me. I thought he was flirting with me. When I went home he still tried to follow me. He thought I was a transvestite, and he actually wanted to have sex with me.* Luiza narrated: *they say: 'Luiza does not need to do gym because her body is already well-shaped'. I do not like to expose my body because it is different. I do not wear pants because they show too much. I do not like clothes that show arms and belly because they are the parts that have more muscles. I am not trying to fend off people. This is more intended to avoid embarrassment.*

Overlapping relationships between body and gender allow interlocutors to recognize BSS as a *male syndrome*, insofar as it becomes *burdensome* in women's daily lives due to the features that approach the pattern of Western masculinity. As in the experience of transvestites, the body of women living with BSS is between male stoutness and female vanity, where the latter denounces and heightens the first, generating social estrangement⁴¹. Thus, the subject-body of women living with BSS contrasts the macho and sexist model of Western woman characterized by the docility-vanity-delicacy tripod. Despite stigmas, prejudices and discriminations, Paula says: *regarding my body, I do not feel different from any woman.*

In addition, women interviewed reported difficulties to have a sentimental relationship with men because of their physical appearance – note the description of each. Interlocutors stressed that prejudice and discrimination affect their self-esteem and self-image, which can lead to situations of isolation and social deprivation. In addition, they produce uncertainties about the possibilities

of sentimental relationships and building a 'normal' family. *They told me that those who had the syndrome could not have a normal life, such as dating, getting married and having children. However, one day, a girl got married and led a normal life (Paula). I worry about getting old and not having anyone to take care of me. However, I do not even know if I'll be alive a few years from now (Kelly).*

Therefore, according to interlocutors, the muscular body, in general, was an element of masculinity, and benefited them, as explained by Pedro (28 years, white, Catholic, heterosexual, single and without girlfriend, secondary school completed, resides in Acari-RN with family, employed in the textile industry): *for us men, it is a bit lighter, because it is common for people who do not know the syndrome to see us as a muscular men.*

On the other hand, according to interlocutors, the body was experienced as ambiguous, depending on the severity of the individual clinical condition. Such ambiguity marked their experiences with the disease through stigmatization, prejudice and discrimination. On the other hand, for both sexes, staying shirtless and wearing beach clothes are practices that are avoided because of the size of the abdomen, the evidence of umbilical hernia and visible blood vessels. In short, the experience of living with BSS, in the viewpoint of our interlocutors, places the body as a space-time where territorialities, history, culture, biology, and statements cross and materialize.

Final considerations

This study sought to analyze the experience of people living with BSS in the Brazilian Northeast. The socio-anthropological perspective made it possible to know the social construction of polysemy and the discursive disputes around the BSS, or *disease of the Magi*, as a background in which the experience of people living with this genetic and rare long-term illness is inserted and produced, according to the biomedical and epidemiological rationale, respectively. In this study, the place of food and of the nutritional diet, of the body and of the gender relationships in the experience with the disease were highlighted. In this process, the theoretical and methodological arsenal of qualitative research contributed with intersubjective experience in the field, its artisanal nature and the situations of otherness that it aroused.

The study allowed us to understand how the management of food and nutritional diet is

guided by prescriptions of health professionals, providing disintegrated actions of social values and meanings of food and eating, aiming to achieve a healthy standard of living, monitored by tests. At the same time, it exposed negotiations and creativity of the subjects that translate concretely into strategies that seek to circumvent the “self” technologies established by agents of modern medicine. In this process, subjects imbricate tastes, values, habits, biomedical prescriptions and pleasures involved in commensality situations. The category of ‘consciousness’ is also pointed out, which can mean reinterpreting biomedical knowledge, from its sociocultural matrices, and allows a greater arsenal of management strategies.

Regarding corporeality, the study allowed us to understand that representations and experiences with the body of people living with BSS show gender inequalities, produced by knowledge and rigid social practices that delimit the

corporal standards imposed for men and women. Furthermore, it exposed the coping with the stigma through episodes of ritual erasure that slow down for man in adulthood, whereas for women, the permanence of a foreign body requires the perennial production of strategies against stigmatization and social judgment.

Finally, in addition to being a pioneer in qualitative research on BSS, the study has demonstrated that the meanings discussed here about food management and body-gender relationships in BSS experience can serve as a basis for actions of health professionals who work with these individuals in the various therapeutic devices of the Unified Health System (SUS). Indeed, the observation of the cultural universe of each single individual is also fundamental to leverage the dissemination of knowledge about BSS in an integrated, relational and holistic perspective, facilitating the understanding of both the professionals involved and society in general.

Collaborations

EB Damasceno, JG Figueiredo, JMB França and JCD Veras also participated in the collection and analysis of data, as well as the writing of the article. REA Borges participated in the analysis of the data, the writing and the revision of the article. L Melo guided the research, contributing in the design, analysis and interpretation of the data, writing of the article and approval of the version to be published.

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Article submitted 21/06/2017

Approved 25/08/2017

Final version submitted 27/08/2017