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Restless legs syndrome: A qualitative analysis of psychosocial suffering and interdisciplinary attention

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Abstract

The aim of this study is to investigate psychosocial factors related to the diagnosis and treatment of patients with restless legs syndrome. Fifteen patients were interviewed at the Neuro-Sono Outpatient Clinic, Universidade Federal de São Paulo. The results were submitted to a qualitative analysis. We identified four content categories: illness description, illness history, illness experience, and relationships. Lack of control over the body and lack of recognition by professionals produce stigma and lead patients to suffering. The research underscores the relevance of psychosocial factors to the diagnosis and treatment of patients with restless legs syndrome and the importance of having interdisciplinary teams when attending patients with restless legs syndrome.

Keywords

gender, interdisciplinary care, qualitative research, restless legs syndrome, suffering

Introduction

Restless legs syndrome (RLS) is a neurological disorder that affects sleep. It is clinically diagnosed based on the International Restless Legs Syndrome Study Group (IRLSSG) criteria (Allen and Earley, 2001a; Allen et al., 2003b; Chaudhuri et al., 2001; Earley and Silber, 2010; Ekbom, 1945; Prado et al., 2002; Walters et al., 2003).

RLS prevalence worldwide is a variable that suggests that genetic and cultural factors may have an important role in its incidence (Rangarajan et al., 2007; Tan et al., 2001). Genetic and physiologic studies on RLS are being carried out intensively, but data on cultural features possibly involved in the expression and prevalence of this disease are still scarce (Pichler et al., 2008; Winkelmann and Ferini-Strambi, 2006).

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The most marked characteristic of RLS is the presence of unpleasant sensations in the legs that are associated with an irresistible urge to move them. Symptoms occur mostly at night and improve with movement, at least while patients keep moving. Sensation involves an individual's ability to feel or detect stimuli derived from the external or internal environment (Martin, 2000; Nolan, 1996), allowing a cognitive interpretation of stimuli that results in perception. Sensation also describes a complex physical and psychological state associated with RLS. Patients' subjective experiences are difficult to measure and even to convey which contributes to the difficulty in diagnosing RLS and perpetuates patients' suffering (Quevedo and Coghill, 2007). Patients and physicians do not always understand the stimuli that start or perpetuate symptoms, making it difficult for them to elaborate on the illness experience (Abbagnano, 2000; Kleinman, 1989; Martin, 2000; Nolan, 1996).

Sensations can be modulated by the attention given to them and the individual's sociocultural integration (Martin, 2000; Nolan, 1996). Meanings given to bodily phenomena are socially constructed through experience and language. The cultural context, in which patients develop and socialize themselves, influences their attitudes, their ways of feeling, and how they organize their experiences (Marcuse, 1987; Quevedo and Coghill, 2007). For patients with RLS, an important aspect of this cultural context is gender.

As a cultural feature, gender (Butler, 1990) can contribute to differences in the prevalence and experience of suffering among patients with RLS, who present unusual behavioral and social interactions and, therefore, different ways of suffering (Das, 1997). Social suffering results from the effects of political, economic and institutional power on people and, conversely reciprocal, from how these forms of power themselves influence responses to social problems. Included under the category of social suffering are conditions that are usually divided into different areas of concern, conditions that simultaneously involve health, welfare, legal, moral, and religious issues, present in a set of chronic illnesses (Kleinman, 1989).

Literature on patients' perspective of living a chronic illness, as some neurological disorders, shows important psychosocial impacts, including the syndrome of demoralization with distress, loss of self-esteem, helplessness, and subjective incompetence (Komárek and Šmídová, 2007; Mohr et al., 1999) or illness intrusiveness (Poochikian-Sarkissian et al., 2008). The RLS could be understood within this same framework, considering, however, that there are no studies about RLS psychosocial impacts.

Although a well-known disease among physicians around the world (Happe et al., 2008), RLS is still a burden to many people who do not understand it and live with the condition for decades in countries where populations do not have enough information about this health condition. In Brazil, RLS is unknown even to many physicians, which contributes to patients' prolonged suffering with this condition (Eckeli et al., 2011; Masuko et al., 2004).

Studies on history and experiences of patients with RLS, considering sociocultural dimensions such as gender, suffering, and the public health context, are important for drawing up interdisciplinary interventions that fully treat patients (Thomas and Watson, 2008). Further research within this field is still necessary to develop an appropriate approach for the Brazilian health context. The objective of this study was to investigate if and how psychosocial factors are relevant to the diagnosis and treatment of a group of Brazilian patients with RLS.

Materials and methods

Participants

From 2000 medical files, we identified and analyzed the 60 patients (42 women, 18 men; aged 31–86 years) with confirmed RLS diagnoses from the Neuro-Sono Outpatient Clinic, Universidade Federal de São Paulo (UNIFESP). Patients were followed up between March 2005 and May 2006. Two of the authors (G.F.P. and

Table 1. Demographic data for the 15 patients (P) in this study.

P	Sex	Age (years)	Education	Occupation	Marital status
P1	Female	78	Elementary school	Pensioner	Widow
P2	Female	51	Incomplete university level	Retired	Widow
P3	Female	72	Elementary school	Retired	Married
P4	Female	69	Elementary school	Retired	Married
P5	Female	55	Incomplete elementary school	Embroiderer	Married
P6	Female	26	University level	Baby sitter	Single
P7	Female	48	High school	Cobbler	Married
P8	Female	67	High school	Retired	Divorced
P9	Female	74	Incomplete elementary school	Housewife	Married
P10	Female	41	Incomplete elementary school	Saleswoman	Married
P11	Male	63	University level	Retired	Married
P12	Male	29	High school	Accountant	Married
P13	Male	71	High school	Retired	Married
P14	Male	61	High school	Retired	Single
P15	Male	61	Elementary school	Retired	Married

L.B.F.P.), physicians with experience in diagnosing and treating RLS, made diagnoses in accordance with IRLSSG criteria (Walters et al., 2003). All patients with RLS were evaluated clinically and neurologically and were classified as severe, according to The Johns Hopkins Restless Legs Syndrome Severity Scale (JHRLSSS) (Allen and Earley, 2001b; Allen et al., 2003a). We invited these patients consecutively and randomly when they were returning for their regular medical consultations at the outpatient clinic. The patient inclusion process was completed after 15 interviews (10 women aged 26–78 years and 5 men aged 29–71 years), according to data saturation criteria, a social point of redundancy in relation to the information collected (Banister et al., 1994). Participants (Table 1) signed the consent form, and the study was approved by the Research Ethics Board (#01104/05) of UNIFESP.

Interviews and data analysis

Qualitative studies are particularly well suited to exploring bodily and social experiences such as RLS, although currently they have only been used in research on sleep disturbances (Broström et al., 2010; Fleming et al., 2009; Hsu et al., 2009; Moseley and Gradisar, 2009; Tse and Hall, 2007). We must stress that we do not make generalizations beyond the study group. Semistructured interviews (Banister et al., 1994) were conducted by M.J.V.V., a psychologist with experience in qualitative research, with a mean duration of 90 minutes and on a specific day following patient inclusion.

After going through introductory formalities and the investigation protocol, which included getting patients' life histories, interviews continued with the following leading question: *How do you feel about your restless legs?* This gave patients an opportunity to provide narratives of disease history, suffering, and relationships. If such topics did not arise spontaneously, the interviewer asked participants about them, following a set of previously elaborated questions (Table 2). Interviews were transcribed and submitted to a thematic content analysis (Bardin, 2007), a method that allowed us to analyze and understand patients'

Table 2. Semistructured interview guide.

What kind of sensation is this?
What names (nicknames) would you give to what you are feeling?
How and when did it start?
Are there other people in the family who also have these sensations in their legs?
Do you know other names that are given to this sensation?
What do you do (have you done) to obtain relief?
What time do you go to sleep?
What is it like for you to fall asleep?
What is your routine before going to sleep?
What are other people's reactions regarding your complaints?
Have you ever heard any comment from members of your family, friends, or physicians (health professionals in general) about that? What was it?
What is it like to live with these sensations?

in-depth descriptions of different situations and processes through categories related to the research problem. As a language-oriented method, the thematic content analysis uncovered what participants think about their subjective and social RLS experiences (Giorgi, 1997; Spink, 1993).

The analysis followed the following steps: (1) three researchers with experience in qualitative methods conducted an exhaustive reading of the interviews, seeking a global understanding of the material; (2) researchers identified the meaning units and classified all the interviewees' speeches; (3) for each meaning unit, researchers constructed a specific text that shows what all the participants said about every meaning unit; and (4) after that, researchers proposed a *meaning picture* that represents RLS and the social process to which it belongs.

Results

Data analysis identified the following categories in participants' speeches: illness description, illness history, illness experience, and relationships (Table 3; Figure 1).

Illness description

Participants describe this category from two psychological perspectives: sensations and perceptions. For them, RLS sensations are something weird and unnamable that lead to suffering and that someone say "isn't pain" (P4, P5); in addition, RLS sensations presented an intensity often externalized with the expression "it's difficult" (P3, P5). The presence of this sensation led to the individual's feeling that his/her body is out of control. In the words of female participants, the sensation was "horrible" (P3, P7), leading to a state of agony and to feeling "mad, crazy, ashamed, and humiliated" (P1, P7, P9). Weirdness is associated with suffering. Words and expressions like "something weird" (P2, P8), "horror" (P2, P7), and "torture" (P7) punctuated their discourse. In contrast, the words of male participants referred to RLS as a "discomfort" (P11), something unexplainable, and "a sad thing" (P15). Terms used by women and men to describe such sensations were often grouped by contrast: according to physical sensations/internal states ("little animals walking"(P4)/"restless" (P5)); movement/resting ("sand blocks collapsing inside my legs" (P13)/"numbness" (P15)); depth/surface ("something eating from inside" (P11)/"itching" (P11)); and control/lack of control ("jerking" (P1, P12)/"deep itch" (P11)). The disease appeared to be a piece of the body, that is, the legs. In one patient's words, it was as if the legs were a separate entity: "… and it's just that piece of leg, I am that piece of leg" (P7).

Table 3. Categories.

	Example of quotations from respondents
Illness description	
Restless legs syndrome is associated with something weird, unexplainable, unpleasant sensation, discomfort.	I don't have a name to give to this sensation. It's something strange (P13). I feel agony and anguish; it's hard to explain. It's a sensation of agony that squeezes the chest and bothers me (P2). It isn't pain. If it's pain, you take an analgesic and it goes away; it's not pain, it's not tiredness, it's agony (P4).
Illness history	
They report sensations before the triggering of the disease.	I fall asleep (…), and then I walk around the house like a zombie because I'm so tired (P6). I started to notice that I wasn't sleeping when I was about 25 years old (now she is 72 years old). I never was the type of person that sleeps a lot. I had no peace to sleep (P3).
They indicate the origin of disease and when it started.	It started after the "stroke" (P15). It started during my first pregnancy, 17 years ago, at a lower intensity and then it grew more and more serious (P7). After the pregnancy, it continued, until today (P10).
They turn to palliative care for symptom relief.	To have relief, I massage my legs with alcohol and herbal lemon tea. And walking … (P9). Another thing that brings relief is cold water (P12). To kick, while walking (P15). When the movement can be free, with no one near to criticize, the feeling is one of relief (P14).
They indicate the results of the medical treatment after recognition of the disease.	I obtained a good improvement using medication. I cried with emotion when I found out there was a treatment. Good for the legs, good for the head. I avoid taking the medicine, because the doctor said it's addictive. I'd been suffering with this problem for eight years. After I started the treatment I felt rejuvenated by 8 to 10 years (P4).
Illness experience	
The attempt to give the sensations a name evokes opposites such as physical sensation/internal conditions, movement/resting, depth/surface, and control/lack of control.	It's like a shock, a jolt, electric energy. It (the leg) jolts, an electric shock, it jumps (P12). It's as if there were little bugs, and when you look there's nothing there (P4). It's as if it was an itch and the only way to scratch it is walking (P11).
After a bad night with insomnia, they report the performance of routine activities as "rough day," "wanting to sleep and not being able to," "feeling of a badly slept night."	When I work a lot, I get tired and sleep comes, but suffering comes with it (P7). Falling asleep is torture (S2). As soon as I lay down it started, during the day it wouldn't, because I didn't stop (P5).
About chronic illness, they make analogies with resignation, talk about continuous treatment as being at the mercy of the disease, and they do not see any sense in this.	There's nothing that can be done. There's no choice; you have to accept it (P1–P11). The only thing I'm conscious about is that this thing will live with me forever; I'll have to manage it (P11). I've always had this problem (P3). From then until now, I've always had this strain (20 years) (P1).

(Continued)

Table 3. (Continued)

	Example of quotations from respondents
They report daytime activities as distractions from symptoms and an urge to be active.	During the day, when I took care of things, I went this way and that way and didn't feel anything. We can't stop (P1). I lived for my job. The first days of retirement were great. After everything was fixed, I'd lie down, staring at the ceiling and asking myself: What will I do today? (P11)
Relationships	
Restless legs syndrome can be seen with understanding or criticism by family.	My husband respects it. He doesn't say anything. Just asks, "So, have you taken your medication?" I just have to wait for it to go (P3). I think she (the wife) is very understanding (P13). My mother said it was growing pains (P6). My father says it's adrenaline (P12).
Since the illness is unknown, it leads to incomprehension, prejudice, and disregard.	I get completely embarrassed about not being able to control myself, I don't talk about it with other people. It's hard to explain how the feeling is to someone who doesn't have it (P6). My work colleagues make fun of me; they sit on my desk and shake their legs. I prefer the sensation to the presence of people—no one near me to criticize me (P2).
The marathon of consultations because of lack of knowledge and disbelief by everyone, even physicians.	It's psychological. It's a fixation. It's a tic (P8). Do some exercise and it'll go away. I went to all sorts of medical specialties, from vascular to neurologists. Four years ago, I was treated by a neurologist that I trust and I took them [medicines]. It didn't work (P7).

Illness history

With respect to diagnosis and treatment, patients said it was difficult to specify when they first noticed RLS symptoms. Looking back, they talked about a persistent suffering in their daily lives that was associated with physical and internal sensations and that made their daily routines "harder" (P4). Participants said that they were overcome by an urge to move and be active. There were several ways in which they were aware of this condition. Some noticed it after nights during which they slept poorly, others after a stroke, during pregnancy, or during hospitalization. From those moments onward, they worked to avoid these sensations. Measures taken to seek relief included leg movements, such as "stretching" (P11) and "walking" (P15), or stimuli provocation that competed with the discomfort. There was no time left over to take care of themselves because participants deliberately chose to pile their habitual tasks on top of each other. Women chose to busy themselves with daily routine activities, such as handicrafts and domestic chores even after nights of poor sleep. Among men, retirement was translated into activities that would occupy them and tire them out, so that their nighttime sleep could be, to some degree, more satisfactory. Diagnosing the illness often occurred late in their life, many times because of lack of knowledge: some physicians did not believe patients' symptoms or even mistook them for other illnesses. Treatment with medications frequently brings true relief, if patients comply with treatment instructions. However, patients sometimes reported a fear of possible side effects, and doubts regarding the safety of medication worsened patients' experience of suffering. Not everyone reaped the full benefits of treatment: personal, family, and social issues are linked, and sleep "doesn't get 100%" (P11),

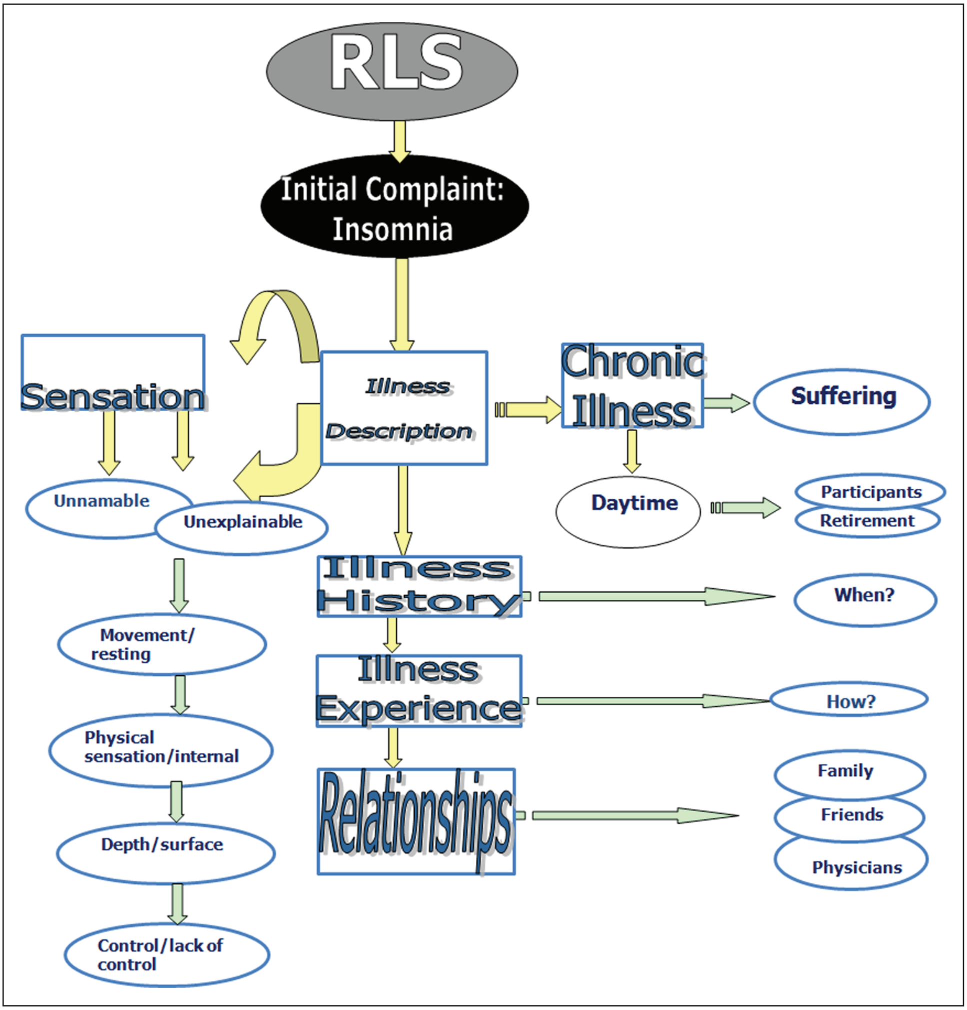

Figure 1. Flowchart of content analysis.
RLS: restless legs syndrome.

that is, some patients are still not getting enough sleep. The cessation of unwanted sensations in the legs through medication and restorative sleep were connected to knowledge of diagnosis, the ability to give a name to the sensations, and feelings of being cared for and understood regarding their suffering.

Illness experience

Insomnia appeared as an initial complaint. In their life history descriptions, patients reported difficulty in sleeping. They had not slept well in a long time, possibly since they were young or since they retired, and this lack of sleep affected their daily routine. In the words of the women in our study, complaints of not sleeping were linked to daily activities and problems performing their routine. Men made connections between sleep issues and experiences of working/not working. The patients also made references to worries about relationships in the work environment. Insomnia is a sign to them that RLS is a chronic illness, a realization that leads to an attitude of resignation. Participants had to learn how to live with RLS, but the continuous treatment worried them. Feelings of impotence stemming from the loss of control of their bodies appeared frequently, and patients experienced hopelessness and sadness regarding their inability to get rid of this condition that "imprisoned" them. The nature of chronic illness and the continuous treatment it requires predisposed patients toward mood instability, indignation, and, consequently, suffering. Both starting treatment and receiving medical guidance also confronted patients with the chronic nature of RLS. A patient's experience of illness swings from anxiety over a condition that does not make sense to the realization that he/she has a chronic illness—two different moments of suffering.

Relationships

Regarding their relationships with family and the social effects of their condition, participants said that something was bothering them physically and mentally, which disturbed their lives and relationships. With RLS, reactions from family members range from comprehension and sharing to criticism and nonacceptance of the illness. Women participants said that their children had difficulty in understanding their mother's symptoms, and they refer to RLS as "a woman's thing" (P5) or even "madness" (P2, P7). Patients with RLS do not talk about their condition with friends to avoid the embarrassment and emotional exposure that accompanies a poorly understood illness.

Patients' attitudes do not change even after being diagnosed and becoming educated about RLS. They say many times they feel comfortable only among other patients with RLS. Regarding Brazilian patients' relationships with physicians, the greatest complaint was that some of these doctors were not familiar with RLS and were unable to make a diagnosis. Many patients felt humiliated, disbelieved, criticized, and mocked, and they were sent off for a marathon of unnecessary appointments and examinations. Some physicians believe RLS symptoms to be a psychological issue, causing patients to feel guilty and responsible for their uncontrollable symptoms.

Discussion

To the best of our knowledge, no other study has described patients' subjective experience of suffering in relation to RLS. In this study, we choose to deal with suffering as a psychosocial category, instead of using the concept of quality of life. In fact, studies have ever shown that RLS condition has a significant impact on patients' quality of life (Abetz et al., 2004, 2005). However, in our view, quality of life questionnaires could not be adequate to study patients' experiences of suffering with RLS since their history is central to this study. Qualitative research addresses a patient's life history and the process by which the illness progressed, not just the patient's present RLS condition.

Participants' demographic and psychosocial characteristics (gender, age, experience of suffering, individual routine, narrative of life and illnesses, occupation, and health support) are central in their representation of illness and frequently expressed in each of the categories of analysis.

Data analysis uncovered the way these patients saw themselves and were seen by others and raised subjective and intersubjective questions that consider the suffering caused by living with unnamable sensations, by not understanding the nature of one's disease or even by other people's disregard.

Regarding illness description, participants disclosed an incredible set of meanings and often recognized that they could not name or explain exactly where and what the sensation was: sometimes it was something internal, or nonspecific, or something that did not make sense to them, for example, a pure sensation, like a feeling of agony. The struggle to name these sensations revealed, from the beginning, a suffering that cannot be stopped by time or more information. When label is missing from a psychosocial experience, as it often is in RLS, a person does not recognize the subjective and social place he/she must occupy and suffers as a result (Das, 1997).

With respect to illness history, patients presented concerns about diagnosis and treatment (having an unknown disease, how hard it was to decipher bodily sensations, what to do to find relief) that revealed another perspective of RLS representation that results in suffering. Even if we cannot generalize these findings to a larger population, we noticed differences among men and women related to gender roles. Both groups discussed the activities of their daily routines in their illness histories, but whereas women with RLS try to occupy themselves with domestic routines, men tend to be engaged in work activities. Even if these strategies bring some relief, it seems that they work only if those participants find an acceptable gender-specific way to manage the condition and sustain their day-to-day lives. Although we noted that RLS sensations are the same for men and women, the meanings they ascribe to their experiences are related to the effective management of what they experience as insomnia. Among men, retirement brings with it the notion that people are embarking upon a phase of inactivity when another stage of life is likely to begin, that is, chronic illness. It is like an episode of life that pertains to elderly people: entering the nonproductivity stage or even becoming sick. Immobility is associated with stopping working and causes an intensification of the perception of RLS symptoms in this group. Here again, gender behavior expectations, a social and historic construction (Burman, 2007), are key to understanding differences in participants' experience of suffering.

With respect to patients' illness experience, insomnia is presented as the main RLS symptom and the reason for seeking medical care. Patients mention insomnia as something hard to overcome, which initiates the experience of suffering. Relief for this suffering lies not only in the elimination of insomnia but also of the strange sensations in their legs. The experience of chronic illness in patients with RLS goes beyond the mere perception of what goes wrong with their bodies and touches their personal and social lives. Among these patients, especially the elderly, RLS was an unknown chronic illness for decades. In their relationships with many physicians, patients create expectations regarding attendance, treatment, drug effects, and the possibility of being cured. Not being believed by some physicians had a detrimental effect on patients. In addition, the inability to label symptoms transcends physical disease, showing up in the social and cultural arenas as well. As patients recounted, the chronic nature of RLS causes life changes, suffering, and affects social performance. In fact, a chronic illness controls patients' lives by making them slaves to continuous treatment or even subjects them to chronic suffering (Kleinman, 1989). Patients' discourse on RLS comes together with the literature when they refer psychosocial experiences of having a chronic disease, as in the syndrome of demoralization and deterioration in relationships (Komárek and Šmídová, 2007; Mohr et al., 1999). However, RLS has significant differences in relation to other chronic diseases, since it is an "invisible" illness, whose symptoms are sensations that can be measured only by clinic evaluation. Then, as we have seen, its potential to cause adverse psychosocial effects seems higher.

Concerning relationships, patients have doubts about physicians and treatments, and they need new points of reference for thinking and acting. For patients with RLS, other people's failure to validate symptoms is a source of anxiety, frustration, and dissatisfaction, that is, suffering. Doubts and perplexity lead to added suffering: patients perceive being sick, live with the illness, and have no answers about their symptoms, causing them feelings of shame, anger, or despair (Kleinman, 1989). Stigma, a concept loaded with cultural nuances, arises when a physician or a person close to the patient is not familiar with RLS and says that women with this disease are hysterical or in menopause.

Patients, families, friends, and physicians are in the same symbolic context. In these relationships, patients' suffering creates a need to discuss and gain understanding of their experiences. Patients can live with and accept illness within a framework of confidence that another person believes and sympathizes with them. When patients find a physician who is able to understand them or who is already knowledgeable about RLS, they experience long-hoped-for relief. Patients' discourse also contains indicators of resistance to submission within the set of relationships, which may signify the desire to assert their individuality. This means not only becoming visible but also gaining the capacity for transformation, thereby ceasing to be an object and becoming the master of his/her own destiny within the society and culture to which he/she belongs (Carvalho, 2008).

Despite the increasing interest in RLS, the availability of specific drugs to treat it, support groups for patients and families, and tools for assessing its severity and making proper diagnosis (Happe et al., 2008), we see how difficult it is still for Brazilian physicians and patients with RLS to arrive at diagnosis and treatment of the disease. Although the efficacy of treatment warrants discussion, we will only note that when patients with RLS look for treatment, there is still little knowledge among Brazilian health professionals about RLS, which leads to the nonrecognition of patients' suffering. This situation is explained by the emphasis in our medical culture on specialization at the expense of interdisciplinary approaches to medical education, a situation that has been discussed before within the framework of health policy priorities (Machado et al., 2011).

Even if within a qualitative research, resulting themes and conclusions are limited, we understand that our results point to very important questions about health care offered to chronic patients, especially when their experiences are connected to stigma associated with gender role and mental health condition. In fact, the gender role differences suggested by the results must be taken as an invitation to a larger sample of investigation where these differences could be more explored and understood.

Although we support the idea that the qualitative approach is the most appropriate for studies on patients' bodily experiences, we acknowledge that researcher bias and preconceptions may have influenced our findings. Consequently, we welcome multiple independent researchers to review the transcripts from our study, following a systematic method of evolution that both improves the reliability and validity of results and minimizes researcher bias.

Conclusion

This study shows how psychosocial factors are relevant to the diagnosis and treatment of a group of Brazilian patients with RLS. Many Brazilian patients have lived with RLS symptoms for decades, many years before IRLSSG criteria and JHRLSSS had been established. Lack of control over the body, gender-based discrimination, and lack of recognition among professionals have produced the stigma surrounding this disease. The result is failure to care for medical and psychosocial needs of patients with RLS, leading them to feelings of hopelessness and suffering. Caring for patients with RLS involves both attending to the suffering caused by the disease itself and the pain associated with the disbelief and humiliation they have endured.

An interdisciplinary clinical approach that considers cultural, psychological, and physical health factors is especially important in the Brazilian context, where patients need more resources to cope with the challenges of RLS. An interdisciplinary team, including a physician, psychologist, physiotherapist, occupational therapist, physical educator, and so on, could come to a fuller understanding of persons suffering from RLS, their individual histories, narratives of their suffering, and their social and cultural contexts. The goal is to attain a better understanding of patient and illness, to learn how to deal with the complex nature of RLS, and to connect effective treatment to a better lifestyle.

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