
“THE BODY I WAS AND THE BODY I AM”: CONCEPTIONS OF WOMEN WITH ALTERATIONS CAUSED BY LEPROSY¹

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¹ Paper elaborated based on the results of the dissertation – What the body reveals and what it hides: women with bodily alterations caused by Hansen’s disease and their implications for self-care, presented to the Graduate Nursing Program at *Escola de Enfermagem Anna Nery (EEAN), Universidade Federal do Rio de Janeiro (UFRJ)*, 2010.

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ABSTRACT: The aim was to understand the conceptions of women about the female body with alterations caused by leprosy. In this qualitative and descriptive study, the concepts of the theory of representations were applied. Participants were 43 women with bodily changes caused by leprosy, who regularly attended a referral unit specialized in health dermatology. Individual semistructured interviews were held and thematic content analysis was used. The results show body conceptions related to health (past) and disease (present), showing the strength of esthetics and body functionality, influencing these women’s participation and social integration. In conclusion, these women’s body conceptions explain their self-care practices, and knowing them helps to ensure that nursing can better meet their care needs.

DESCRIPTORS: Nursing. Nursing care. Leprosy. Women’s health.

“O CORPO QUE EU FUI E O CORPO QUE EU SOU”: CONCEPÇÕES DE MULHERES COM ALTERAÇÕES CAUSADAS PELA HANSENÍASE

RESUMO: Objetivou-se compreender as concepções das mulheres sobre o corpo feminino com alterações provocadas pela hanseníase. De natureza qualitativa e descritiva, aplicou os conceitos da teoria das representações. Participaram quarenta e três mulheres com alterações corporais causadas pela hanseníase, frequentadoras de uma unidade de referência especializada em dermatologia sanitária. Realizou-se entrevista semiestruturada, individual, e análise temática de conteúdo. Os resultados mostram concepções de corpo relacionadas à saúde (passado) e à doença (presente), mostrando a força da estética e da funcionalidade do corpo, influenciando na participação e inserção social destas mulheres. Conclui-se que as concepções das mulheres sobre seu corpo explicam suas práticas de cuidado de si e, conhecê-las contribui para que a enfermagem possa melhor atender as necessidades de cuidados destas mulheres.

DESCRIPTORIOS: Enfermagem. Cuidado de enfermagem. Hanseníase. Saúde da mulher.

“EL CUERPO QUE FUI Y EL CUERPO QUE AHORA SOY”: CONCEPCIONES DE MUJERES CON ALTERACIONES CAUSADAS POR LA LEPROSA

RESUMEN: Se objetivó comprender las concepciones de las mujeres sobre el cuerpo femenino con alteraciones provocadas por la lepra. Estudio de naturaleza cualitativa y descriptiva, que aplicó los conceptos de la teoría de las representaciones. Participaron cuarenta y tres mujeres con alteraciones corporales causadas por la lepra, frecuentadoras de una unidad de referencia especializada en dermatología sanitaria. Se realizó entrevista semi-estructurada, individual, y análisis temático de contenido. Los resultados muestran concepciones del cuerpo relacionadas a la salud (pasado) y a la enfermedad (presente), mostrando la fuerza de la estética y la funcionalidad del cuerpo, influenciando en la participación e inserción social de estas mujeres. Se concluye que las concepciones de las mujeres sobre su cuerpo explican sus prácticas de cuidado de sí, y conocerlas contribuye para que enfermería mejore la atención de las necesidades de estas mujeres.

DESCRIPTORIOS: Enfermería. Atención de enfermería. Lepra. Salud de la mujer.

INTRODUÇÃO

The research problem emerged from care practice to leprosy patients, when it was empirically identified that women distinguished care behaviors for their body changed by leprosy, differently from men affected by the same problem.

Thus, the female body altered by leprosy was delimited as the research problem, based on the premise that the body of women marked by the disease with any visible disability comprises a subjective universe that can damage the way this woman reflects her self-image, influencing self-care and the way of relating with the world.

In the context of this study, the female body with bodily changes due to leprosy represents a biological, historical, social and cultural construct, produced and reproduced in multiple ways in different times and places¹ and, thus, a source of thousands of meanings and representations in the female social imaginary that can influence self-care.²

Thus, the central research question aims to map women's conceptions of the female body, chiefly in case of important physical changes related to leprosy.

The justification for this attempt is based on the fact that the body is the symbolic system for which culture serves as a framework, determining the differences that will constitute people's identities according to their conceptions of the world and the social means they are inserted in.³ As the body serves as an important reference to structure one's personal and subjective identity, personal inter-relations are influenced by the subjects' images and mental representations of one another, which can facilitate an approximation or, on the opposite, lead to distancing, in those cases when the image established is not compatible with what they see as acceptable.⁴⁻⁷

Women in particular tend to be identified in terms of their physical appearance as, nowadays, it is seen as a determinant of self-valuation that marks the female gender. The self-image concept, however, is not only based on morphological evidence of the own body, but also on psychosocial and historical factors.⁸

Thus, women whose body leprosy has changed are confronted with a multi-faceted reality, which impels them towards intra-psycho (objectivation and anchorage) (re)learning about their new female condition. This acceptance of their new image can turn into a source of personal

conflict. Their ability to accept and adapt to these changes directly affects their emotional status, quality of life and personal, family, social and professional functions.

Hence, to study the body conceptions of women with changes caused by leprosy, further understanding is needed about representations of the disease and the meaning of their new body's language, as well as acknowledgement of their difference, without perceiving it as a deviation that can stigmatize them and lead to their isolation from themselves and other people.

In other words, the aim is to understand the women's conceptions about the female body in a singular situation of illness, as the changes a given disease, in this case leprosy, provokes may show that the daily experiences of women with this disease about what their body reveals (the bodily changes that are objectively present) and what it hides (real and imaginary conceptions of the body) and their actions and reactions towards the meaning of having this disease can indicate forms of care delivery.

METHOD

This research is characterized as qualitative, exploratory and descriptive, about a Social Representations⁹ phenomenon - the body. For the analysis of its conceptions, Social Representations Theory (SRT) was applied.¹⁰

The concepts sustaining this theory adhere to the study design as, in its epistemological perspective, the women who are the subjects of this study are considered creative beings who elaborate and re-elaborate their daily thinking. This historical and social construct gives rise to representations about leprosy.

In the same way as the gender concept, the body concept is socially conceived as well. This permits saying that the analysis of conceptions in search of the SR phenomenon that comprises the female body issue offers one out of different routes of access for a given society and social group. The body experience is always modified by the experience of culture, as the social structure is symbolically recorded in the body.¹¹

Studies beyond the biological, which unveil women's representations about their altered body and its implications for self-care, underline the subjectivity that makes these women choose, transform and fully incorporate the care, which is part of the set of professional orientations. To decide

on self-care, women with bodily changes due to leprosy need to understand what is happening to them, which demands self-knowledge and reflection about the disease. Thus, the intersubjectivity needed for the process of self-knowledge, self-acceptance and self-care is evidenced in this study, in line with the premises of SRT.¹²

The context was the Specialized Referral Unit (SRU) in Health Dermatology, maintained by the Pará State Department of Public Health (SESPA), which delivers outpatient care to patients with skin diseases of health interest, forwarded from Primary Health Care Units (PHCU) in urban and rural areas of the state.

Subjects were 43 women with bodily changes caused by leprosy, who were under treatment or had been discharged (cured). Data were produced between July and November 2009. Information was collected on consultation days at the different clinics (medical, nursing, physiotherapy, psychology, among others), after a previous consultation of the patient files. The selection was based on the following inclusion criteria: 1) Being of age in legal terms, i.e. between 18 and 59 years old; 2) Living in the cities of Marituba and Ananindeua, Pará State; 3) Being unrolled at the institution selected as the study context; 4) Undergoing any kind of treatment: medication or having been discharged, but continuing treatment for reactional episodes, or undergoing physiotherapy or occupational therapy to prevent physical disabilities; 5) not being pregnant and puerperal; and 6) not being a former inhabitant of the Marituba colony.

Qualitative information¹³ was constructed through individual interviews based on a semi-structured script. Interviews were tape-recorded, in combination with manual records in a field diary about the subjects' facial and bodily expressions with a view to articulation between verbal and bodily (non-verbal) expressions.

Thematic-categorical content analysis techniques were applied to the produced material.¹⁴ In a pre-analysis, the main lines were identified that organized discourse, which were based on the time (past and present) and biomedical reference (health and disease) framework. Based on these two frameworks, the discourse produced on the research problem was organized per theme, structuring the thematic categories.

The thematic categories were named by applying the magnitude criterion, that is, based on major trends in the discourse.

It should be mentioned that transcriptions

maintained the characteristics of the North, expressed through specific jargon. The women's identity was preserved through the alpha-numerical identification of the testimonies, in which the letter I means interview, followed by the sequence number in which interviews were held and the letters A and M in superscript, which indicate the cities of origin, i.e. Ananindeua and Marituba.

To develop the study, the ethical guidelines of National Health Council/Ministry of Health Resolution 196/96 were complied with. The project received approval from the Research Ethics Committee at *Escola de Enfermagem Anna Nery, Universidade Federal do Rio de Janeiro*, under protocol No. 31/2009.

RESULTS AND DISCUSSION

The participants are between 18 and 59 years old and their ages were stratified in three age groups, divided as follows: 18-29 years; 30-41 years; and 42-59 years. Most of the women (19), i.e. 43%, were between 30 and 41 years old. No difference was found between the other groups, each of which contained 12 subjects.

Female body conceptions were constructed based on main lines that organized the discourse, for which a cut-off was established between the body of the past and the body of the present. This timeline is not necessarily based on the chronological criterion, but on the delimitation the disease diagnosis provides. In that sense, the time framework intersects with the biomedical framework, which contains the hubs of health (past) and disease (present).

The past refers to health, what one had, what one was, what one lost, and the present relates to disease, what one is going through, what one is, what one has (not what one gained, as the disease is not referred to in the discourse in the sense of a gift). In the construction of body conceptions for the women under analysis, this clear distinction exists between the former and the current body, objectively demonstrated in the question the researcher was asked when she asked the women to talk about their body:

[...] *when? Before or now? It used to be more natural. Not today [...]* (I17^M).

[...] *before or now? I didn't have these "stains" before, now there are always these things appearing, like: wounds. I used to sunbathe a lot, go to the beach... not today [becomes silent]* (I19^A).

[...] *how I see my body now?* [talks weeping]

Totally unrecognizable. I cry when I see my body like this, because I didn't have these ugly things before, and now I do. That hurts a lot [lowers her head and voice] it hurts the body and the heart even more (I22^M).

[...] I feel very bad about my body, after this problem I got, the leprosy. Then various problems came up. It's... [hesitates] it hampered me, pain problems, I feel a lot of pain. Then, I feel very bad. I don't feel like I did when I was fine. Now I only live ill [mumbles] (I6^M).

After defining this organization, the conceptions were communicated based on themes that attempted to classify the past and present bodies in the search for meanings for what they experience in their disease. The esthetic and functional dimension takes form and directs feelings of estrangement, the formation of the new image, new meanings and self-care.

Esthetic dimension of the body

This dimension is based on the bodily changes and their repercussions for the physical as well as the affective body, as well as the meanings the women attribute to their body.

The beautiful (healthy) and the ugly (sick): significant elements in the construction of representations

The beautiful and the ugly are adjectives imposed on the body image and serve to classify people in society. Based on this classification, groups, gains and losses are defined and even occupations of social spaces are determined.¹⁵

The application of thematic content analysis techniques shows that beauty and ugliness co-occur with the classification of the healthy or sick body. Both classifications emerge as antagonistic and well-outlined hubs, without much possibility of mutual exchange.

[...] my body was always handsome; I was always the cutest one in the family. Then, when the disease came, it left these sequelae and mutilated me a little. I don't know if you've seen my hands and feet [shows her feet and hands, cries, asks for a handkerchief and dries her tears], mainly my right foot. I had this thing with my right foot, it was normal, all normal, like when we're born. Just that [hesitates] due to a nail hole, that turned into a piercing, that piercing left sequelae, gradually affected the bones. That's what became of it [raises her hands to the height of her eyes and looks both the back and hand palm] and that already made me disappointed because I couldn't use an open shoe as I used to anymore. Today I only

use sneakers, because I have to hide them [pause, eyes lowered, weeping tone]. I'm ashamed, you see? (I1^M).

In 96% of the testimonies (41 women), the concept of bodily perfection is based on the absence of skin alterations. Thus, images of perfection and cleanness are linked to what would be the perfect body in their opinion. Thus, the beauty and the ugly would be conditioned to skin integrity which, according to them, should be smooth, without stains, clear and well hydrated.³ These expressions objectify the image of a perfect, healthy, beautiful body.

Perfect body? Humm... I see that beautiful body, smooth, clean, everything right... without leprosy... like that body I had before this disease (I4^M).

Seven interviewees used the terms "complete woman", "whole woman", "whole body" in the attempt to explain the transformations and losses that occurred in their "body that was" healthy and beautiful.

I do not find myself a complete woman because of the disease. According to me, a real woman is a healthy woman, in good health. I differ from the others. I am a woman, but I do not longer feel like a whole woman, a woman like I was before (I4^M).

A body of a woman with bodily changes caused by leprosy makes me think of mutilation [...] I lost a part of me [pause] [crying]. Also because, when I had the surgeries, I was losing a piece of my body, and each piece I was losing [hiccups and lowers her head], like a bone [hesitates, rises her hands at the height of her face, looks fixedly at her hands, raises her shoulders and cries compulsively], meant that I was losing my body, that body I was born with. I think of it as it was [looks upwards, tries to smile, crosses her arms around her]: marvelous, healthy, perfect, without any problem (I2^M).

Functional dimension of the body

This dimension is based on the ability to make body movements and human actions expression daily tasks, mainly related with the female universe. These tasks were very frequent in the testimonies, as they are strongly connected with gender identity. In addition, professional activities mainly evidenced the functional dimension of the body, which was to be expected in view of the context of the capitalist production mode in force in Brazil.

Being a woman and having one's body altered by leprosy? I think it's bad [...], sad [...]. The pain I feel is constant, it's terrible. Then, if you work, you have to

stop working because the problem distances you from work. You need the rest, the diet, all that [...] (I35^M).

Woman's body? Being entitled to my health, being healthy again to be able to work. I am unable to work [pause] because I feel a lot of pain, those things [...] (I31^A).

The functional dimensions are closely linked with body esthetics, serving to construct these women's conceptions, guiding them in their self-perception in view of the bodily changes and feelings that emerge through the transformations in their body. The healthy body is beautiful and its functions are preserved; the sick body is ugly and its functionality has been compromised.

It changed, like, with the disease, which affected my hand and my foot [shows her hands, gets up from the chair and also shows her feet]. I don't walk anymore like I used to [hesitates]. My hand also changed, lost force, and things fall from it [shakes the hands]. Today my body got really ugly, sick, mutilated [long pause, crying] (I4^M).

Self-concept and self-image are important and influence people's lifestyle. Non-acceptance of the new image, due to the abrupt bodily change, generates self-estrangement in these women. The body transformed into something repulsive and beyond standards changes social life forms and sometimes limits social participations.⁶

How I see myself? [...] horrible, I'm afraid of not getting well anymore, everything hurts [...] my body is full of knots, full of large and red plates. I look like a monster [crying]! (I11^A).

I've already arrived at different houses where the people already know what I have. That makes people feel really bad [...]. Then I even got out of there because I was already mistrusting that it was because of the leprosy problem. We ask for a glass of water and it seems that that person does not want to give water, then I no longer went there because I know it was because of that. I felt really bad about the person 'ah, you've got that!' She didn't even say that, she actually said like, in those times when it was uglier: 'ah, you're... you're leprous! You've got that problem, that's why you're ill and gonna get worse, you're gonna get all rotten' (I6^M).

In the analysis of the data corpus in search of the women's conceptions about their body altered by the leprosy, expressions are identified that denoted objectifications and anchorages,¹⁶ in the efforts the women made to given a new meaning to their bodies. Expressions like "rotten", "leprous", "frog leather", "snake skin" and "rotten bean" are pejorative terms some participants used to name

their own appearance. The fact is noteworthy that these expressions almost always appeared connected with prejudice and co-occurring with this theme. On the other hand, the frog and the snake are considered poisonous animals, which cause fear and repulsion, objectively translating the feeling they develop about themselves, in their self-perception of their body related to other people's observed reaction.

One aspect of anchorage in the pop singer Michael Jackson's figure is also highlighted, who is publicly known for the countless transformations he went through, ranging from facial traits to skin color.

How I see my body? A leprous body. Now, I don't even like to look at it. I got fat and the disease gradually ate away my entire body [...]. But I'm very hopeful that I'll be fine (I14^A).

After I started this treatment, things improved completely. My skin got a bit better. It's just when I get these reactions that it gets like this, then people say: 'ah, your skin got even better, because it's like a frog's leather, I don't know [...], all speckled [...]. Isn't there a frog that's all speckled? 'I've gone through a lot of discrimination already [...] (I22^M).

Today? I see my body differently. My skin, that upsets me, annoys me due to the transformation. I won't say it's just because of the fat mass. But mainly due to the stain, 'cause it got dark, my skin. That upsets me a lot. I tell my mom that what happened to me, I think it's a bit of what happened to Michael Jackson. Because he was one person and turned into another and that was how I felt and still feel. For now I still feel, because I see that my skin is dry, stained and I feel like a snake changing skin [...] (I26^A).

Today I feel like a rotten bean [...] Each time I sort beans and see a rotten one in the middle, I have to separate the rotten from the good ones. That's how I'm feeling now: being obliged to separate from other people because, sometimes, I feel some kind of discrimination, even inside my own home (I10^A).

Self-image interferes in interpersonal relations due to the feeling of estrangement related to one's own body, causing isolation, shame and fear of rejection and difficulty to accept one's new bodily image.¹⁷ These feelings anticipate the prejudice and rejection they will definitely be subject to.

Look, honestly, I'm ashamed of my body, also because, after I finished treatment, I still haven't approximated anyone [...]. I don't know if that comes because I got disappointed in the person I had. Then I [hesitates] get scared [hesitates] of getting close to

anyone and getting disappointed again. That he won't understand and get prejudiced, why did I go through all this? (I27^A).

Being a woman and having one's body changed by the leprosy? To me that means not looking at oneself in the mirror due to the stains; it means being ashamed before people. To me, it's [hesitates] it's feeling a bit of [hesitates] self-rejection due to the stains, because, sometimes, you cannot hide all stains [...] (I29^M).

Both dimensions, esthetic and functional, emerge as references for women to think about their body and, from this point onwards, they look for strategies to overcome the difficulties and keep on investing in their lives.

Strategies to overcome

Living with one's new body and self-care

To cope with and adapt to their new bodily reality, the women attempt to keep on living through the sublimation of the disorders these bodily changes have caused.

The sublimation of the disorders the bodily changes caused takes form through the women's contact with people who, according to their perceptions, have worse alterations than their own.

[...] although my change is not that intense yet. It won't get there, with God's help, it won't get that intense. Due to everything we're seeing here, however, at this unit, when we are waiting for our turn in the corridor, and each time a case comes by [...]. I don't get terrified, but it alerts me. I stay alert so that it won't get there. Because, thanks God, I can still say: Oh dear, she's worse than I?. Ah, this morning, I saw a body; he was feeling bad because of a drug, his face was full of stains. The boy was, he was already a young man, his head lowered, he was ashamed. So, so as not to reach that stage, I have to take the medication and give up some things (I28^A).

We have to overcome it, we need to have will-power to overcome it [...]. We have to think that there are people with worse problems than ours, much worse [...]. Sometimes we think that our problem is bigger than other people's, but we hear people say: 'Oh dear, that...', 'Damn', 'I'm fine compared to that person, right?' (I30^A).

The feeling of impotence towards the bodily changes experienced entails situations of conformation with the problem, so that they can experience and live with the limitations the disease and its resulting alterations cause.

For me it's normal, I have conformed myself. I

have to conform. What can I do, doctor? Can I make my fingers get straight? Can I get back to walking normally? All that's left for me is to pretend that I've got nothing and 'let life lead me', as Zeca Pagodinho says (I31^A).

In parallel, however, the women do not stop taking care of themselves and self-care emerges applied to the bodily changes, in the attempt to recover their bodily integrity, minimizing the changes.

Today, when [hesitates] I get up and lie down, I use creams, just for the feet, just for the hands, for the body; I use bath oil. I take care with skin cracks, with marks, because [hesitates] if you like it, you take care of it. So, I [hesitates] I need to take that care with my skin. So, to me, when I see a little stain, I feel agonized; I quickly put on some cream. I don't like to shave my legs, also because I don't have that much hair either, but [hesitates] when I can, I want to sunbathe a bit again, because that's what I like (I17^M).

The results presented here underline research performed in France about bodily SRs,¹⁸ and about SRs of health and illness,¹⁹ as well as other research results from Brazil about bodily SRs in nursing care.²⁰ In that sense, it strengthens the hypothesis that the functional dimension of the body may be a hegemonic representation, as it is part of the bodily SRs in the above mentioned research.

The negative disease burden is expressed in feelings of sadness, verbalized and objectified through looks and other non-verbal communication forms, captured in data production and registered in the field notes.

The implications of female body conceptions based on the esthetic dimension reinforce the importance of this dimension in social participation and integration as, with a body conceived as ugly, women decide to get isolated and greatly restricts her participation in social activities, as these expose her to a possible rejection.⁶

Rejection is objectified in the women's discourse through reports of real situations experienced in their daily life, and also in the fear they feel that this will happen. Rejection often lies in the future, in what may come to happen, that is, the women anticipate an imagined rejection and protects herself against the exposure.

One form of self-care refers to the action of getting occupied²¹ and, therefore, there is an urgent need for self-knowledge, which demands that these women return to themselves through actions related to attention, looks and perceptions, so as

to know what is important for self-care. And that is one of the practical applications and contributions of this research for care delivery to women with bodily changes due to leprosy: beyond health care related to clinical aspects of the disease and traditional forms of coping, professionals can help them in the process of attributing a new meaning to their body and, thus, take care of themselves, intensifying skin care, color, physical exercise, weight control, functional maintenance of the body, among others.

Self-care requires knowledge and self-observation with a view to greater awareness of what is harmful in their routine habits, in their form of acting and thinking.³ Thus, care delivery to these women requires the reconsideration of approaches based on the valuation of the meanings they attribute to their body and on the encouragement of self-observation of their body, turning them into treatment allies, giving them a more active and participatory place in their treatment.

CONCLUSIONS

Even if these women get discharged and are considered cured, the leprosy is present through bodily sequelae, marking their lives in a prolonged way, making them assume a hostile attitude towards their own body in the present, as opposed to their body of the past – the body that was lost together with their health.

The suffering these women presented due to the changes they experienced showed to be a traumatic event, due to the changes in their lifestyles as a result of the circumstances the situation experienced at that moment imposed, due to distancing from friends, from the workplace, in short, from everything that was part of their daily life: what was.

For the sake of contributing to the subjects, it is emphasized that, at the end of formal research data collection, there was an opportunity for further interaction between the researcher and these women, including the establishment of a therapeutic relation, which involved health education with a view to a dialogue about the disease, its treatment, medication and related care, mainly regarding diet. In this dialogue, the contents they produced themselves in response to the questions that were asked were recovered, so that they would gain awareness about the application of this care as allies to recover what they had lost through the experience of the disease,

pointing towards a dialogical and reflexive care mode, based on the meanings the care subjects themselves constructed.

In that sense, based on the results of this exploratory research on the body conceptions of women with bodily changes caused by leprosy, further research is necessary to search for social representations of the body and link them with self-care practices as, through access of the SRs, knowledge is possible about the action dimension that responds to these representations.

Further research, including the application of SRT as a whole, will permit mapping the field in which the SRs are structured, identifying the elements that articulate in the formation of these representations, granting visibility to the subjects' information, attitude and self-care practices, supported on the cultural field these SRs are established in. This will put nursing in better conditions to plan and intervene with a view to health care delivery to these women that is more in line with their needs and desires.

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