

PERCEPTIONS ABOUT OCCUPATIONAL THERAPY IN THE CARE OF PATIENTS WITH  
LEPROSY

PERCEPÇÕES SOBRE A TERAPIA OCUPACIONAL NO CUIDADO AO PACIENTE COM  
HANSENÍASE

PERCEPCIONES ACERCA DE LA TERAPIA OCUPACIONAL EN LA ATENCIÓN DEL PACIENTE  
CON LEPROSA

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The objective of this paper is to present the perception of health professionals working with patients affected by leprosy on the performance of occupational therapists within the care team to that patient. This is a qualitative study carried out in 2012. For this purpose an ethnographic nature observation was performed at the *Instituto Estadual de Dermatologia Sanitária* (State Institute of Sanitary Dermatology – IEDS in Portuguese), in the city of Rio de Janeiro, RJ-Brazil, which allowed monitoring activities conducted in the service and seven interviews with professionals working in the area were carried out. It was found a difficulty, both for users, as other professionals, to understand the contribution of occupational therapists in comprehensive care to Hansen's disease.

**Descriptors:** Occupational Therapy; Public Health; Leprosy; Rehabilitation.

O objetivo deste trabalho é apresentar a percepção dos profissionais de saúde que atuam com o paciente acometido pela hanseníase sobre a atuação do terapeuta ocupacional dentro da equipe de atenção a esse paciente. Este é um estudo qualitativo desenvolvido em 2012. Para tanto foi realizada uma observação de cunho etnográfica no Instituto Estadual de Dermatologia Sanitária – IEDS, na cidade do Rio de Janeiro, a qual permitiu o acompanhamento de atividades do serviço e foram realizadas sete entrevistas com profissionais atuantes na área. Constatou-se uma dificuldade, tanto por parte dos usuários, quanto dos demais profissionais, em compreender a contribuição do terapeuta ocupacional na atenção integral à hanseníase.

**Descritores:** Terapia Ocupacional; Saúde Pública, Hanseníase; Reabilitação.

El objetivo de este trabajo es presentar la percepción de los profesionales de la salud que trabajan con pacientes afectados por la lepra en la actuación del terapeuta ocupacional en el equipo de atención al paciente. Este es un estudio cualitativo hecho en 2012. Para ello se hizo una observación de naturaleza etnográfica en el Instituto Estatal de Dermatología Sanitaria - IED, en la ciudad de Río de Janeiro, RJ/Brasil, que permitió el seguimiento de las actividades realizadas en el servicio y fueron realizadas siete entrevistas con los profesionales que trabajan en el servicio. Se constato dificultad, tanto para los usuarios, como otros profesionales, para comprender la contribución de los terapeutas ocupacionales en la atención integral a la lepra.

**Descriptores:** Terapia Ocupacional; Salud Pública; Lepra; Rehabilitación.

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## INTRODUCTION

The World Health Organization (WHO) defines leprosy as a major public health problem, and the cases of this disease are concentrated in seven countries: Brazil, India, Madagascar, Mozambique, Myanmar, Nepal and the United Republic of Tanzania<sup>1</sup>.

The WHO epidemiological bulletin<sup>2</sup>, of August 27, 2010, says that the India reported 133,717 cases in 2009, and Brazil, 37,610 cases. This data shows that Brazil is the second country in the absolute number of cases, however when comparing the population of the two countries, Brazil takes the first place in terms of prevalence rate.

Regarding the treatment of leprosy, therapeutic regimens that are standardized according to the classification of the disease, called multidrug therapy (MDT), are used. For paucibacillary cases, the treatment time varies from 6 to 9 months, and for multibacillary cases, treatment can reach up to 18 months<sup>2</sup>.

Care actions to leprosy are comprised in three levels: in primary care, in medium complexity and high complexity. The primary care activities include health promotion, diagnosis, treatment and prevention of disabilities, as well as health education, both individual and collective. Medium complexity includes actions of diagnosis and specialized therapies. In the highly complexity, assistance is multiprofessional and multidisciplinary, including surgery to repair sequelae<sup>3</sup>.

For more complex cases, the Reference Centers offer a comprehensive, more specialized service. In the state of Rio de Janeiro the State Reference Center is situated at the State Institute of Sanitary Dermatology - Curupaiti (IEDS), located in the city of Rio de Janeiro.

This institute was one of the first hospitals for isolation of leprosy patients, recognized in 1931 as a colony-hospital of the national capital, at the time located in Rio de Janeiro; but it has already functioned as such since 1928<sup>4</sup>.

Currently, leprosy control programs, with a view to its diagnosis, treatment,

prevention of disability and rehabilitation advocate actions that should be shared by different health professionals, acting, ideally, as a team, in all levels of care, from primary care to more specialized levels, as Reference Centers<sup>5,6</sup>.

The team is necessary for relational care process, and this meeting is important in the search for maintenance and/or recovery of some way of living life. And the meetings between professionals and users produce relations of listening and accountabilities that constitute the ties and commitments about the health production, favoring care<sup>7</sup>.

For comprehensive care to patients affected by leprosy, a minimum team of professionals is required, consisting of doctors, nurses, nursing assistant or technician, physiotherapist and occupational therapist<sup>8</sup>.

Occupational therapy, more than acting in physical rehabilitation, believes in motion, in change and transformation of the individual with some disabling condition. The holistic look at the individual is one of the foundations of this profession, since its performance is intended to promote functional independence to people, whether it is in the daily basic activities, in work, leisure or in social life in general.

Given the importance of occupational therapy in the care of people with leprosy, this article aims to present the perception of health professionals working with patients affected by leprosy on the performance of the occupational therapist within the care team to this patient.

## METHOD

This article presents data from a qualitative study with ethnographic approach, held at the State Institute of Sanitary Dermatology - IEDS, in the city of Rio de Janeiro - RJ. The observation allowed monitoring of activities performed in the service.

Six interviews were conducted with health professionals from various fields who work in this institution, to understand their perceptions on occupational therapy in this context.

Interviews were recorded with the consent of the participants and transcribed for analysis. The following inclusion/exclusion criteria were used: being working with people affected by leprosy for more than two years and being inserted in the multidisciplinary team of the Institute. The material obtained was subjected to thematic content analysis.

The project was submitted to the Research Ethics Committee of the Fluminense Federal University, and was approved at a meeting on 05/06/2011, following all the ethical principles necessary for its completion. People who agreed to participate in the interviews signed a free and informed consent form, which contained information and research objectives.

## RESULTS

As a result of ethnographic incursion, the universe of study was composed of six professionals from different areas, who have been working at the clinic for 1 to 27 years. To preserve the identity of these professionals, they were not distinguished by specialty or by working time at the institute, because, since the team is small, it could favor the identification. Speeches elucidated in research are presented below, and professionals are identified by P (professional) followed by a number (1-6).

One of the occupational therapists interviewed talked about the roles that each professional developed in the dermatology clinic of the Institution:

*Social worker has a role of first contact with the patient, the guidelines of all the issues related to which rights they have and which they don't have. Regarding psychologist we do not forward all patients, only when we realize that there is a change, when it's hard then we forward them, not all patients undergo psychology, no. Nursing deals with the medicines, the healing, care, guidance too and even prevention. There is a professional that works with me, she fabricates insoles and I prescribe them. The physiotherapist deals with a general part, she's not very connected in leprosy, she serves everybody but like a general thing, there isn't a specific work. So*

*much so that the orthopedist here does not forward to the physical therapist, he forwards to me (P 5).*

The dermatology clinic in question does not develop work related to activities of daily living, but the guidelines on self-care are made in the occupational therapy service during disability prevention actions, as reported below:

*I act in leprosy disability prevention. Prevention is done in the following way, every patient, at the time they are diagnosed the disease, undergo a neurological evaluation that is made by occupational therapists. And after that, if we do not find any problem they will do a reassessment every two months or when the patient has any complaints. When we realize that there is some change, this patient is more closely seen. Then we shelter them more, we're always seeing that patient. And with some of them we have to start exercises, and give more incisive guidelines when the patient has some change in sensitivity and they may be burnt or injured without feeling and we give care guidance and also guidance on exercises for preservation of what they have and even to improve, depending on the length of time and damage of injury. We try to assess patients on the day they come mainly in passing, the patient comes once a month to take the dose and the medicines, so we use this moment to see them, but we have autonomy, if we need to see the patient next week, I schedule and they come. There is need of awareness about the problem, to give a very warmth welcome too, because prevention of disability is not only telling: you cannot burn and so on. It involves welcoming the person, guiding about what the disease is, to demystify it. Here we have gained a lot of space. When I started working here there were two OTs working here, there was a work already, it was not as valued but they already had their space. I think we achieved a lot because they believe in our assessment. We interfere in corticoid dosage, in corticoid indication. I evaluate and tell the doctor that the patient is getting worse, he makes the corticoid indication, even if he did not see the patient he trust what I say. Sometimes he speaks, let's wait another week to see, we won't give the corticoid now. So in*

*case of neurites, all patients are seen by us, patients with reactions, we kind of forward people, to the doctor and OT to define what will happen to this patient, how we will deal with the corticosteroid, which dosage will be. We discussed a lot, they demanded a lot. But we were bombed, we went through many bombings. So I would tell, I don't know, and then they would stay until we know. If there was any different nerve they would call me. You have to learn if you're here you have to learn (P 5).*

The function of some professionals, from their self-report is evident in the statements below:

*We evaluate all patients with diagnosis of...suspected leprosy and if it's confirmed we monitor the care. It depends, but we always evaluate when the patient starts treatment and when the patient is discharged. And in that interval if the patient has any complication depending on what it is we may see the patient once a week or every two weeks but usually I see the patient every two or every three months depending on the clinical picture. But it's always in very beginning and at discharge... I think it's valued, because they... I think they have learned to respect and to know the work, especially here at the clinic, I'm not taking about there up, in the hospital right? But I think here at the clinic, I think they see it as an important aid. (P 2)*

*I think it is very important for us, I think since it is not something that is so dependent on, how am I going to say, on equipment, it is not such a medicalized, technician approach, it is more... I'm not going to say playful because you don't like, but you know, I think it's better, I think it's the professional who fits perfectly to the type of thing we need to do. (...) Then there is the doctor who has to tell it, they have to have that speech and every time at every consultation, then there is nursing at the time the drug is being administered, they have to see, they have to ask if the patient has any injuries, give him support, prevention to disability, social work, we have a luxury here, there is also a psychologist, not every place has this, and not every place acts this way, focusing on rehabilitation, as you are emphasizing. (P 3)*

With regard to the practice of occupational therapists in accordance with other professionals it was said:

*(...) we are here in the hospital so lucky to have a good group of occupational therapists, I notice that they work with very specific activities, often with physical disability prevention, directed to people who are already healed, but who has since retired or something like that, who are without an occupation in life. I think they are fundamental in the health team, I've been working here for 10 years and I haven't had in other hospitals the experience of working with OT and here I have a lot. So I think they complement the team, they are part of the team in the fundamental truth, especially in the clinic with disability prevention work. I think it reflects a lot, for example if I was able to make a move that I was failing to do, if I can work accordingly despite my limitations and take up my time with it, I can handle such treatment, I can get better. I think it works a lot with this thing of hope of really being fine. I think this is fundamental. (P 1).*

*I think in relation to physical therapy, it is very mixed regarding prevention of disabilities, it's very mixed right? This isn't very clear, no (P 2). It is very, very, very, very [important], directing, guiding the way to act, how to proceed in their activities of daily living, you know, how to protect themselves, in our particular case here, therapists have advanced a little and are involved in the manufacture of footwear with insoles, metatarsal bar and these things, I do not even know if this is part of the occupational therapy menu or if it is from ... I don't not know, you can talk about that ... if it's scope of physical therapy, I don't know, but anyway there has been advancements here for that, we have here a quite cool prevention with shoes (P 3).*

*We have, within the... we serve in a certain way, a little different, this issue of occupational therapy and physiotherapy is the great struggle that you have, I know it seems that in the end the occupational therapists are actually physiotherapists, is it or is it true? You want to associate a therapeutic to its occupation process, that a housewife can take for example a broomstick more properly. Let's*

*talk about the ergonomic relationship of a broom to mutilation, there is this kind of thing, isn't it? So what is the relationship? So this is occupational therapy and the physical therapy in a certain way could, at that time, in the act of having to sweep the house, in their daily life in the act of its powers, make an association of a feature for this may... for this disease can be reversed or can be stabilized or can be slowed during the process the patient is performing, or performing their tasks, or performing a task previously determined by therapy in that it can also make an association with this issue as a whole. In every way possible, trying to make this professional as quickly as possible, speaking of capitalist relation to these professionals, they need to go back, they need to be within society, they need to be up right, they need to be in all their conditions and the occupational therapy would be inserted in this process, trying to make that in the functional process right, in their occupations or more they could also have a process, or absorbing a therapy to help them with this greater integration or this higher return, or that they did not evolve (P 4).*

*Their self-esteem, their potentiality as a person you know? Because it is a disease like any other, we know that it is discriminated, it leaves sequelae, but they have to be different, this is what we have to show them, so I think that occupational therapy can show this a lot, not only in leprosy that it's its goal, but in other diseases, you know? More or less, I will not say to you that I know well the occupation itself, right, but it is my impression, I may be wrong, you know, but it would involve enabling patients to seek their skills or their potential to use the body somehow or in a leisure activity or manual work, I don't know if it's right, you know? It had to be more widespread, because there is little space, right? (P 6).*

## DISCUSSION

The multidisciplinary team plays key role in care for people affected by leprosy. The Ministry of Health defines a core team for different actions and complexities of care to attend people affected by leprosy. This team is composed by doctor, nurse, nursing

assistant or technician, when the service is classified as type I, developing health education activities, epidemiological surveillance, diagnosis, neurological assessment and the degree of disability, examination of contacts, treatment, monitoring and prevention of disability with simple self-care techniques<sup>8</sup>.

Within the multidisciplinary team, the occupational therapist can promote actions related to the functional performance of the patient in their daily life activities, to their participation, autonomy and independence in their home environment and community.<sup>9</sup>

Occupational therapy in the care of leprosy uses intervention strategies to guide patients on the prevention of disabilities, functional autonomy and integration in community<sup>10</sup>. This professional will be mediator for the user to develop a sense of responsibility for their own health, both in the care level of rehabilitation, as in the preventive level.

Guidance for the user, at the time of reception, was precarious as shown through this study. With the practice of a well-conducted guidance, professional tends to approach the patients and to make them responsible for their development, whether in the rehabilitation process, prevention of disabilities or in the diagnosis and treatment. When the user is invited to join the health care team, who works with them as co-responsible for their treatment, the result tends to be a conscious, committed user, multiplier of information.

It is interesting to assess the causes of failure in fully providing information, from the professional to the patient, about the conduct and procedures performed. When professionals do not explain what they are doing, how and what the purpose of what they are doing is, they do not allow users to distinguish what is being done and what that professional's attributions are. It can be understood, as part of this, the insecurity of professionals in giving "powers" to the patient when he/she understand better their behavior.

One can see, through the reports, the focus of occupational therapy at the institute

is the prevention of disabilities, even as its specialty, and there are not many actions for the rehabilitation and group care. This also appears in the accounts of professionals from other areas on the definition of the profession.

There are reports in the literature<sup>11</sup> on the group experience with patients affected by leprosy coordinated by occupational therapist addressing issues relating to the disease, such as disability, daily life activities, in order to improve the functional capacity. From that group, it was perceived minimization of difficulties by all participants, such as reduction of contractures, improvement in sensitivity and moisturizing the skin, among others. The group with patients generated improvement in self-care, as well as personal valuation and better conditions to overcome the constraints of disease.

During interviews in IEDS, professionals have defined the tasks of occupational therapy in various ways, such as performing activities to occupy patients' time, as similar to physical therapy and as related to functionality and everyday life.

According to scholars<sup>12</sup> in the area of occupational therapy, in ancient times it was believed that diseases were caused by the devil and that, to heal them, one had to work, exercise or do crafts to "occupy" the mind. Thus, the precursor school of occupational therapy was the moral treatment, which called for the implementation of occupational activities in nursing homes to provide the healing of the sick people, as well as to raise funds for the institution.

These historical facts about the early occupational therapy can influence its definition by other professionals. Another frequent issue is the non-distinction between the actions of this profession and physical therapy. In care to the person affected by leprosy, professionals trained to perform the evaluation of the degree of incapacity are occupational therapists and physical therapists, which contributes to maintain this confusion. As seen in the studied clinic, occupational therapy performs predominantly actions of evaluation of the

degree of incapacity, and there was difficulty in defining the roles of the two professions.

Some theorists of occupational therapy area report that the profession is subject to a plurality of definitions, since it brings together different schools of thought and there is no a single correct answer about its definition<sup>13</sup>. In this sense, it can be seen that, despite the different approaches given to define occupational therapy, respondents were able to report what is essential in the care process to people affected by leprosy.

There are three ways to define occupational therapy. One of them defines the profession by the resources used, other, defines it by the relationship between therapist-activity-patient, and the last one defines the profession by the work object, i.e., the human doing, its occupational performance<sup>14</sup>.

Data analysis showed that professionals defined occupational therapy consistently with their level of relationship with the occupational therapist, not determining what is right or wrong in their actions. Many of these perceptions are clearly linked to the experience of professionals in dealing with the occupational therapist. The way the occupational therapy professional carries out their profession defines the understanding of the universe around them and about their work. An immersion in the research site at other times showed that many students in the process of finalizing their training in the area also had incorrect definitions and failures regarding the role of the occupational therapist.

Added to this ignorance about the profession, there is unpreparedness of the professionals, stigma and neglect associated with leprosy, which leads to the following result: Brazil is the first country in the world in prevalence of the disease, with 12% of diagnosed cases presenting disability at the time of discharge, 2% of cases without evaluation of the degree of incapacity and still 42% of cases with evaluation, but without filling this date at the time of notification.

**CONCLUSION**

Conducting field work is not an easy task. The data collection process in an institution with so many meanings becomes a process of participation in the history that is known there. It is not possible to build information about this service without considering the history, the stigma, the experience of the people that make this institution so unique among many others throughout Brazil.

There is no doubt, therefore, on the strangeness about the reasons for the presence of the researcher in that context. After successive dialogues and full provision of explaining, the confidence and freedom arising between the researcher and the research participants allowed the collection of data and analysis that support this study.

Occupational Therapy professional, who was present, needs to get a more pronounced role in order to clarify his role. Users, although they identified the people who acted as occupational therapists, were unaware of the concept of the profession.

This professional has a key role in the integration between services and especially in understanding the user as the protagonist of their own story. When these professionals, in turn, understand the importance of their work in the construction of the daily activities of the user, without a doubt, they will be more present in quality change and comprehensiveness of care.

Some challenges must be overcome. Thus, the dialogue between professionals from different sectors, the practice of guidance and full clarification to each patient seen there, the effective implementation of active search and the incessant search for early diagnosis of communicants, the provision of operations and services of rehabilitation and immediate record of all actions taken will be critical in this process.

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#### **CONTRIBUTIONS**

**Luisa Arantes Loureiro** participated in the conception, design, collection, analysis and interpretation of data, article writing, critical review. **Lenita Lorena Barreto Claro** was involved with the conception, design, critical review of the article. **Ivia Maksud** held the orientation in the original research of which this article is an offshoot.