Original Article

Leprosy reactions after release from multidrug therapy in an endemic cluster in Brazil: patient awareness of symptoms and self-perceived changes in life

Reações hansênicas após poliquimioterapia em um cluster endêmico no Brasil: conscientização do paciente sobre os sintomas e auto-percepção das mudanças de vida

Maria de Jesus Freitas de Alencar[1], Jaqueline Caracas Barbosa[2], Thayza Miranda Pereira[3], Suen Oliveira Santos[4], Klaas Hendrik Eggens[5], Jorg Heukelbach[2,6]

Abstract

We assessed diagnosis and consequences of leprosy reactions as perceived by affected individuals. A cross-sectional study was performed in five municipalities in an endemic disease cluster in Brazil. Structured interviews included 280 leprosy-affected individuals who had experienced reactions after release from treatment (RFT), 2007–2009. Open questions included information on diagnostic features of leprosy reactions, sensory loss and self-perceived changes in life after experiencing leprosy reactions. In this study, 43.2% were diagnosed with reaction during multi-drug therapy. In the majority of cases, the patient himself/herself perceived disease symptoms first (n=240; 85.8%). Primary Health Care Centres were the first entry point into the health system for 95/150 (63.3%). In 72.6% of these, leprosy diagnosis was made within the primary care setting. Patient-perceived signs and symptoms of reactions included skin lesions (42%) and neurological symptoms (39%). In total, 216/280 (77.1%) stated that they had perceived changes in life. Physical impairments limiting possibilities to work and reduced income were mentioned commonly (n=118; 54.6%). Discrimination and social isolation were also experienced. Our study indicates an inadequate response of health services for individuals with reactions after RFT. An integrated approach is needed, including physical, psychological care and self-care groups.

Keywords: leprosy; biological reactions; health of the disabled.

Study carried out at Department of Community Health, School of Medicine, Universidade Federal do Ceará (UFC) – Fortaleza (CE), Brazil.

[1] Doctor in Community Health; Researcher of Department of Community, School of Medicine, UFC – MAPATOPI Project; Independent Consultant in Public Health, Brazil and Portugal.

[2] Doctor in Public Health; Professor of Post-graduate Program in Community Health, Department of Community Health, School of Medicine, UFC – Fortaleza (CE), Brazil.

[3] Master in Public Health; Pedagogical Advisor, Centre for Education in Health Surveillance, School of Public Health of Ceará, State Health Secretariat of Ceará – Fortaleza (CE), Brazil.

[4] Physiotherapist; Director of Specialized Care, State Health Secretariat of Tocantins – Palmas (TO), Brazil.

[5] Master in Public Health; Consultant in International Health – Portugal.

[6] Anton Breinl Centre for Public Health and Tropical Medicine, School of Public Health, Tropical Medicine and Rehabilitation Sciences, James Cook University – Townsville, Australia.

Correspondence: Maria de Jesus Freitas de Alencar – Rua do Rio Criz, 1 –Código Postal: 3440-125 – Couto do Mosteiro – Portugal –
E-mail: jesusalencar2@gmail.com

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Resumo

O objetivo foi avaliar o diagnóstico e as consequências de reações hansênicas na percepção dos indivíduos afetados. Estudo transversal realizado em cinco municípios num *cluster* hiperendêmico do Brasil. Entrevistas estruturadas com 280 indivíduos com reações após o tratamento poliquimioterápico (PQT) no período de 2007 a 2009. Perguntas abertas incluíram informações sobre diagnóstico de hanseníase, alterações de sensibilidade no paciente e autopercepção das mudanças na vida depois de desenvolver reações hansênicas. Neste estudo, 43,2% foram diagnosticados com reação durante o tratamento PQT. Na maioria dos casos, o próprio paciente percebeu aparecimento dos primeiros sintomas (n=240; 85,8%). Centros de atenção primária à saúde representaram a primeira entrada no Sistema Único de Saúde para 95/150 (63,3%) indivíduos. Em 72,6% destes, o diagnóstico de hanseníase foi estabelecido dentro do contexto dos cuidados primários à saúde. Os sinais mais comuns percebidos de sintomas de reação incluem: lesões de pele (42%) e sintomas neurológicos (39%). No total, 216/280 (77,1%) afirmaram ter percebido mudanças na vida depois de desenvolver reações hansênicas. Deficiências físicas que limitam as possibilidades de trabalho e renda reduzida foram aspectos negativos importantes (n=118, 54,6%). Discriminação e isolamento social também foram experimentados. Este estudo indica uma resposta inadequada dos serviços de saúde quanto ao cuidado de indivíduos com reações após o tratamento PQT. Uma abordagem integrada é necessária, incluindo cuidados físicos, psicológicos e participação em grupos de autocuidados.

Palavras-chave: hanseníase; reações biológicas; saúde da pessoa com deficiência.

INTRODUCTION

Leprosy is endemic in Brazil, with 33,303 new cases notified and a detection rate of 17,2 cases/100,000 inhabitants in 2012[1,2]. One of the challenges of leprosy control (though rarely addressed by control programmes) is the prevention of disabilities of those released from multidrug therapy. Individuals after release from treatment (RFT) are considered "cured" and deleted from the registers, even when severe neurological symptoms with motor impairments are present. However, this period needs special attention, as persisting peripheral nerve damage may have significant physical, social and economic impact many years after RFT[3-5].

Various studies have shown how complications after release from treatment caused a considerable burden on health services in Brazil[6-8]. Around 30% of patients released from treatment present with reactions up to five years later[9,10]. However, in Brazil still no defined policy exists to provide care for this group[11,12]. Direct monitoring of persons affected by leprosy after RFT by health services is not done systematically. In the 2010 ILEP report (ILEP 2010) reactions after "cure" were described as a source of concern, particularly with difficultly to diagnose and capacity to cause disabilities. These reactions present a challenge for proper management, being difficult to treat and liable to reoccur[13]. To respond to this challenge, a double-blinded multicentre study (TENLEP) started in 2011 to test the effectiveness of early treatment of reactions to prevent nerve damage in leprosy patients[14]. In the light of these challenges, the prevalence and demand for care for patients with reactions remains largely unknown. This holds true for patients on treatment and those who already have finished their anti-leprosy treatment. In this paper we present a study on diagnosis and consequences of leprosy reactions as perceived by affected individuals living in a specific hyperendemic area of Brazil. The data provide information that may help to design effective control measures to prevent sequels after RFT.

METHODS

Brazil's National Hansen's Disease and Eliminable Diseases Control Program has focussed on providing control measures on geographically delimited highly endemic disease clusters, as identified by spatial analysis[15-17]. The disease cluster with greatest geographical extension has been focus of a major research project called "Epidemiological, clinical, psycho-social and operational patterns in leprosy in the states of Maranhão, Pará, Tocantins e Piauí: an integrated approach". The area with a population of about 10 million inhabitants includes parts of the north and northeast regions of Brazil (Figure 1). The area had an average annual case detection rate of 75.6/100,000 inhabitants in the years 2001–2009[18]. The project is known by its acronym MAPATOPI (derived from the four involved federal states Maranhão, Pará, Tocantins, and Piauí). The present study forms part of this project. Five municipalities dispersed throughout the cluster area were included: Araguaína (Tocantins state), Floriano (Piauí state), Marabá (Pará State), Bacabal and Caxias (both Maranhão state) (Figure 1). We selected these municipalities based on the following criteria: population >50,000; being a regional reference centre for leprosy diagnosis and treatment; hyperendemic based on average annual case detection rates (>40 new annual cases per 100,000 inhabitants); and presence of established primary health care services, as evidenced by a Family Health Strategy coverage >70%. The Family Health Strategy in Brazil defined that one Family Health Team (FHT) is responsible for the care of 2,400–4,500 population[19]. This criterion could not be applied to any eligible municipalities in this state of Pará where the Family Health Strategy coverage is very low (36% in 2008). Nevertheless, we

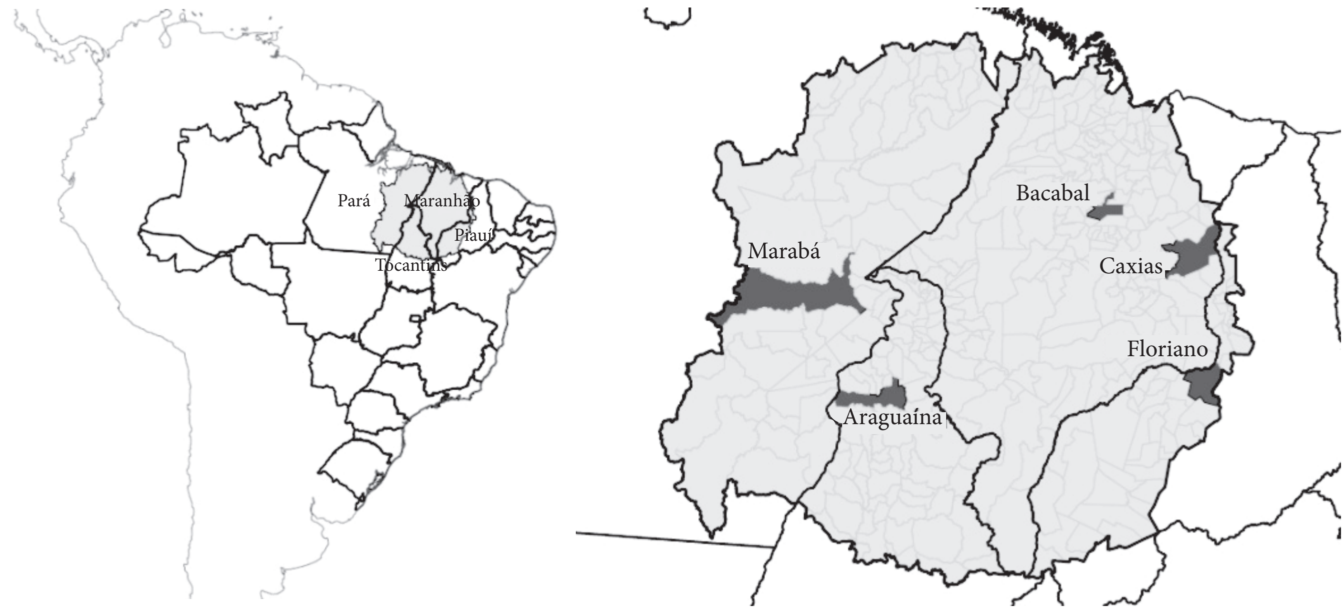

Figure 1. Localization of the study area in parts of north and northeast Brazil, and localization of the municipalities included in the study

Table 1. Baseline characteristics of municipalities included in the study

Municipality (state)	Inhabitants (2008)	New leprosy cases (2008)	Case detection rate/100,000 inhabitants (2008)	Primary Health Care Centres	Coverage of Family Health Program
Araguaína (TO)	119,636	178	148.8	20	(31) 89,8%
Bacabal (MA)	97,946	154	157.2	19	(30) 100%
Caxias (MA)	147,416	130	88.2	34	(47) 100%
Floriano (PI)	57,975	88	151.8	25	(23) 100%
Marabá (PA)	203,048	228	112.3	12	(2) 3,2%

opted to include one municipality from Pará State. Baseline characteristics of the five municipalities in 2008 are included in Table 1. We used the definition of an episode of reaction as proposed by Saunderson et al.[20]. A new episode was considered when reaction–specific symptoms appeared at least three months after a previous reaction episode.

We performed a cross-sectional study consisting of structured interviews in patients after release from multidrug therapy, who had experienced leprosy reactions and were living in one of the five municipalities included. In a first step, patients resident in the study area who had experienced leprosy reactions between 2007 and 2009 (after RFT) were identified during field visits of all primary health care centres and reference centres in the five municipalities, through the analysis of patient records. Patient selection was not dependent on the time of starting MDT. These patients were invited by community health agents to participate in the study. They were requested to present themselves at the respective health centre. If patients did not appear, field workers visited their homes at least twice. Interviews were performed in privacy between October 2010 and January 2011.

Essential socio-demographic data were recorded. We then asked three open questions regarding a) the diagnosis of leprosy disease, b) patient awareness and diagnostic features of leprosy reactions, and c) perceived changes in life after experiencing leprosy reactions. The answers were entered using Microsoft Excel® and Microsoft Word® and were categorized according to groups of signs and symptoms. For instance, "pain in my nerves" would become neurological symptoms. In the first question, "How did you discover that you have this disease?" answers were classified as "self-perceived" and "perceived by others".

Patient charts were perused to obtain clinical data (leprosy classifications, clinical forms, dates and types of reactions, the Disability Grade at diagnosis, at RFT and at the time of the interview). Data were obtained from patient charts and through a clinical examination during the time of the interview. The Eyes-Hand-Foot (EHF) scores were also collected, as this score is more sensitive to measuring change than using the total Disability Grade of 0, 1 or 2.

Data were analysed using Epi Info software (version 3.5.2; Centers for Disease Control and Prevention, Atlanta, USA).

Ethics

The study was approved by the Ethical Review Boards of the Federal University of Ceará (Fortaleza, Ceará, Brazil) through

Document 136 of June 5, 2009 of the Protocol 138/9 and Advice 28/2009 of the Universidade Luterana de Palmas (Palmas, Tocantins, Brazil). The state leprosy program coordinators of the four states involved and the five municipal leprosy program coordinators approved the study. We obtained informed written consent from all study participants, or in case of minors from their carers.

RESULTS

General characteristics and clinical data

Out of 518 eligible individuals with reactions after RFT, 280 (54.1%) were included in the study. The study population consisted of 190 men (67.9%) and 90 (32.1%) women with a mean age of 46.5 years (SD: 16.8; range of 8–85 years). Six <15 year-olds were included. A total of 53 (18.9%) were illiterates. Only 110 (39.3%) were working, whereas 47 (16.8%) were unemployed, 54 (19.3%) retired, 16 (5.7%) working sporadically and 11 (3.9%) students. The mean monthly family income was R$ 1077 (approximately € 441 in 2010). The multibacillary form of the disease was diagnosed in 233 (83.2%) individuals. Most patients had borderline leprosy (n=115 – 41.1%), followed by lepromatous leprosy (n=83 – 29.6%), tuberculoid (n=24 – 8.6%) and indeterminate forms (n=24 – 8.6%); the remaining (n=34 – 12%) were not classified or data were not available. The number of reactions recorded in patient charts after treatment ranged from 1 to 6 episodes. The majority, 217 (77.5%) had one episode, two episodes were found in 46 people (16.4%), three episodes in 13 patients (4.6%), four episodes in 2 (0.7%) and six episodes in another 2 (0.7%). Type 1 reaction was most common (n=104 – 37.1%), followed by type 2 reaction (n=52 – 18.6%) and neuritis (n=39 – 13.9%). Besides, 43.2% were diagnosed with reaction during multi-drug therapy. Information on the type of reaction was not given in the charts of 85 (30.4%) patients. The EHF score ranged from 0 to 10, with 239 (85%) of patients scoring between 0 and 4 and 41 patients with a score 5–10 (15%).

Diagnosis of leprosy and patient journey until diagnosis

A total of 269 (96.1%) responded to the question: "How did you discover that you have this disease?" In the majority of cases, the patient perceived one or more symptoms, mainly dermatological changes such as skin lesions. In this category, 17 noticed skin manifestations because they were more aware due to a family history of leprosy (Table 2). Interestingly, in about one quarter, neuropathy was the first perceived symptom. In 10% of cases, other persons, such as family members and friends noted the disease. In 150 cases (53.6%), information was available on health services visited until diagnosis was made. In 95 (63.3%) of these patients, the primary health care centre was the first entry point to the health system. In 69 (72.6%) of these, diagnosis was made within primary care, whereas 23 (24.2%) patients were sent to a reference centre for diagnosis, 2 (2.1%) to private practice, and 1 (1.1%) cited a mobile diagnostic unit. In 55 (36.7%) cases, diagnosis was made directly in a reference centre bypassing the primary health care system (n=49; 32.7%) and by a dermatological clinic (n=6; 4.0%). Fifty-eight patients (38.7%) were diagnosed with leprosy in a state of reaction.

Self-perceived signs and symptoms of leprosy reactions

Two-hundred and forty-eight (88.6%) patients were aware of their leprosy reaction after release from treatment. Symptoms perceived regarding the leprosy reaction are presented in Table 3. Besides dermatological and neurological symptoms, pain played a major role.

Table 2. Identification of leprosy in patients who experienced leprosy reactions: "How did you discover that you have this disease?"

	n	%
Self-perceived	240	85.8
Skin disorders	176	62.9
Nerve disorders	64	22.9
Perceived by others		
By the family	14	5.0
By friends	6	2.1
By routine health service screening	6	2.1
Through campaigns	2	0.7
Contact screening	1	0.4
Without information	11	3.9
Total	280	100

Table 3. Self-perceived signs and symptoms of leprosy reactions (n=248 interviewed and 274 reported symptoms – 26 interviewees reported more than 1 category)

	n	%
Skin disorders	115	42.0
Lumps and nodules/Type 2 reactions	65	23.7
Reddened lesions/Type 1 reactions	32	11.7
Itching, paraesthesia, blisters	18	6.6
Nerve disorders	97	35.4
Neural pains in hands, arms and legs	28	10.2
Pains, loss of sensation	46	16.8
Neuritis	23	8.4
Muscle dysfunctions	11	4.0
Cramps	5	1.8
Muscle weakness and difficulty in walking	4	1.5
Crooked hands and feet	2	0.7
Other clinical symptoms	51	18.6
Oedema	13	4.7
Joint pains/body pains	15	5.5
Fever, weakness, nervousness	16	5.8
Itching, insomnia	5	1.8
Nasal problems	2	0.7
Total	274	100

Changes in life after experiencing leprosy reactions

In total, 206/280 (73.6%) stated that they had perceived changes in their lives after experiencing leprosy reactions. Table 4 depicts the categorized answers of the emotional reactions and physical consequences as mentioned by the participants. Physical impairments limiting possibilities to work and reduced income were important negative aspects perceived (n=118 – 54.6%). Heavy-duty work (agriculturalists, masons) or professional activities that would need good motor coordination are more difficult in case of nerve damage or lower leg oedema. Several participants said that they had limitations in their activities of daily living (ADL), such as personal care limitations or difficulties doing household chores (n=25 individuals; 11.6%). Another negative aspect was the restrictive nutritional advice ("you cannot eat fatty meat during treatment") given by health professionals, affecting patients eating their routine foods during anti-leprosy treatment. Few (n=33 – 15.3%) had emotional reactions. Social isolation, rejection and discrimination were experienced. For example, one participant stated that after he was diagnosed with leprosy, his wife separated household appliances, burned mattresses and pillows and forced him to sleep in a separate room. Soon afterwards she left him, leaving behind their small children. Another participant, a 47 years-old male teacher, was banned from teaching during anti-leprosy treatment. Fear, sadness and doubts on the possibility to be cured also transpired from the interviews.

Table 4. Perceived changes in life after experiencing leprosy reactions: "Did this disease/reaction bring any new problems/change to your life? Which?"

Changes	n	%
1- Intrapersonal changes	151	70.0
a- Physical	118	54.6
Activities of daily living (ADL)	25	11.6
Muscle weakness and cramps	21	9.7
Pain	17	7.9
Limitation of body movements, impairment	17	7.9
Loss of sensation	14	6.5
Skin changes, "allergy" in arms and legs	8	3.7
Loss of vision	8	3.7
Weight gain	3	1.4
Impotence	2	0.9
Diabetes, high blood pressure	2	0.9
Growth retardation	1	0.5
b- Psychological and emotional	33	15.3
Fear of prejudice; sadness, revolting; not accepting reactions; social isolation	17	7.9
Concerned about permanent lesions	6	2.8
Shame	5	2.3
Suffering; fear	3	1.4
Nervousness/ Mood changes	2	0.9
2 – Changes affecting Social Participation	65	30.1
a- Discrimination	39	18.1
At work, including loss of employment	16	7.4
By the community	14	6.5
By family and friends	9	4.2
b- Social relations	16	7.4
Social life changed/ stopped travelling	6	2.8
Stopped playing soccer, playing the guitar and physical activity	5	2.3
Drinking alcohol, eating food	5	2.3
c- Attitude	10	4.6
Treatment by family or other persons	7	3.2
Rejection	3	1.4
Total	216	100%

DISCUSSION

Diagnosis of leprosy and perceived symptoms and signs of leprosy reactions

Our data show that dermatological changes were often the first symptoms leading to the diagnosis of leprosy. This is well known and has been described in standard leprosy textbooks[21]. In a study by Barbosa[12], with a population of 304 individuals after RFT in two municipalities in Ceará state, northeast Brazil, dermatological changes were the presenting symptoms in 40.6% in Sobral and 47.2% in Fortaleza. This result is easily understood as the Brazilian national leprosy control programme has implemented Information, Education and Communication (IEC) policies that emphasize early diagnosis through dermatological symptoms for a long period. However, Kelly-Santos et al. (2009) found in a study of educational material on clinical signs of leprosy that only 74% of the brochures highlighted dermatological signs (skin lesions, nodules) and symptoms (pain, fever loss of sensation and paraesthesia) of the disease. Experts have defended the importance of the inclusion of information, education and communication (IEC) approach for creating patient awareness, early diagnosis, reaction and the reduction of stigma, thus creating a new image of leprosy[22]. This study gives evidence to the success of this strategy, but points also to the need to strengthen the knowledge on neurological manifestations of the disease. Neurological signs and symptoms are common in patients, but little known or ignored by health workers. A major international study in Indian emphasized the need for early recognition of neurological complications[23]. National leprosy control programmes should include this aspect of the symptomatology of leprosy and leprosy reactions in its training programme and IEC material. Neurological symptoms, such as pain of neural origin, were reported by almost 30% of study participants. Some of these sought health care only when the symptoms worsen. In a study in India, neuropathic pain was present in about one fifth of those interviewed, with dermatological symptoms in a similar frequency as in our study[24]. These signs and symptoms are frequently associated with multibacillary patients, mostly dimorphous or borderline reported that after RFT 88.2% of cases with reactions were MB patients[25]. Patients frequently experienced more than one reaction episode. We found that 23% of the cases interviewed experienced two or more reactions. One patient had suffered six episodes. Another study found 60 patients (26.5%) with a second reaction episode, without specific treatment[26]. This study also point to the need for full clinical investigation of these patients by other medical specialties.

Changes in life after experiencing leprosy reactions

Our study clearly showed how reaction episodes affected both the person's abilities to perform or do their daily activities as well as how reaction episodes restrict their participation in work, family life and others. The histories of fear, sadness and doubts on the possibility to be cured also transpired from the interviews.

According to the WHO International Classification of Functioning, Disability and Health, activities and participation are part of the larger definition of health. It outlines how an individual exercises daily activities and is engaged in social life, taking into consideration the functions and structures of his/her body. These components include items referring to mobility and personal care (washing, cleaning, nutrition, hygiene, clothing and appearance). It also encompasses household activities, other important dimensions of life (education, employment, and economic life), interpersonal relationships and community activities[27,28].

It is well known that after RFT affected persons continue to suffer from major problems including insecurity, fear and loneliness[11]. These emotions are caused not by active disease, but by its complications, like neuritis and reactions. Primary health care services are not always prepared to deal with these problems[11,29]. Problems such as loss of self-esteem, difficulties in daily life activities and discrimination encountered by persons affected in this study were identified in earlier studies[30]. To feel "less than trash", "like a rag", "as useless" are strong emotions, that easily lead to a low self-esteem. It leads easily to affected persons choosing isolation, hiding from everyone and everything[31].

Another potential consequence of continuing leprosy-related problems after RFT is a diminished health-seeking behaviour. After the completion of MDT, the affected person is released and no longer considered a patient but a "cured" individual, and the registers are closed. From an infectious disease medical point of view the patient in fact is cured. However, from a preventive medicine and cultural point of view, sequels associated with leprosy continue affecting individuals and causing interference in both functional activities and social life in many societies, including Brazil. These factors need to be taken into account, providing a more integrated and humanistic care after RFT[32]. Strategies including self-care, Community Based Rehabilitation (CBR) and counselling should be considered. The STEP program in Nepal demonstrates how the self-care groups and CBR improves self-confidence and lead to stigma reduction. The inclusion of counselling within control programs and RFT has also been found to be an important intervention to consider within RFT strategies[33].

Our study is subject to limitations. First, for logistical reasons we focussed on main cities in the disease-endemic cluster, and not in rural areas where the situation may be different. Secondly, open questions may not always be noted in a similar way, as different interviewers were involved in the study. Care was taken to reduce this observer bias and to standardize data collection. The known probability of leprosy reactions occurring in individuals after completing anti-leprosy treatment determines the necessity of clinical monitoring and adequate case management after RFT. This holds especially true in primary care settings as this is the main entry point for care-seeking persons.

CONCLUSIONS

Our study indicates an inadequate response of health services in the municipalities under study regarding care of individuals with leprosy after release from treatment with reactions. Monitoring persons affected by leprosy after release from treatment and cost-effective measures should be a focus of leprosy control and prevention measures in the Brazilian primary health care system. It is necessary to create this monitoring and surveillance system for reactional episodes for a period of at least six months up to five years after RFT. This proposed period takes into account the slow and often silent character of nerve damage development, with its physical and psychosocial consequences. Clearly, an integrated approach is needed including physical and psychological care. The inclusion in self-care groups to improve self-confidence and support. It is important to empower persons affected by leprosy in dealing effectively with leprosy reaction-related events after release of MDT treatment.

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