Factors which influenced the decentralisation of leprosy control activities in the municipality of Betim, Minas Gerais State, Brazil

PRISCILA LEIKO FUZIKAWA*, FRANCISCO DE ASSIS ACÚRCIO**, JOHAN P. VELEMA*** & MARIANGELA LEAL CHERCHIGLIA**
*Municipal Health Department, Betim, Brazil
**Federal University of Minas Gerais, Brazil
***The Leprosy Mission International, PO Box 902, 7301 BD Apeldoorn, The Netherlands

Accepted for publication 26 June 2010

Summary
This is the second part of a study conducted to evaluate the decentralisation of leprosy control activities in Betim, Minas Gerais, Brazil.

Objectives: To identify factors which hindered or facilitated the decentralisation of leprosy control activities in Betim municipality and to evaluate the quality of care after decentralisation.

Design: The study comprised a 2½ hour focus group discussion with 10 professionals who participated in the decentralisation process. The group included health service managers and professionals from different backgrounds and types of health services involved in leprosy control.

Results: The following factors were identified as having hindered decentralisation: staff attitude, lack of staff training, stigma and health system organisation and management. The facilitating factors were: staff training in Betim, existence of a Municipal Reference Centre. The group considered that quality of care improved after decentralisation.

Conclusions: The problems identified cannot be addressed with simple, immediate solutions. They require coordination with partners both within and outside the municipal health secretariat. Ongoing staff training is essential and should be done using existing expertise in the municipality. An easily accessible reference centre is important as a place for training and backup for newly trained professionals.

Correspondence to: Priscila Leiko Fuzikawa, Rua Joaquim Nabuco, 131 Nova Suica, Belo Horizonte – MG, 30480-590 Brazil (e-mail: plfuzikawa@gmail.com)
Introduction

Since the creation of the present national health system in Brazil (Sistema Único de Saúde – SUS) in 1988 health is considered a social right. It includes actions of health promotion, prevention and assistance.

Each municipality is responsible for the health of its population, and should implement health care activities according to national health care policies and to state planning. The funding of these activities is a responsibility of the federal and state governments as well as the municipality itself.

Health care assistance is organised in three levels: primary health care, medium and high complexity. All of the three levels are equally important as integrality is one of the principles of SUS. Medium and high complexity services, when not available in the municipality, should be made available to the population through partnerships with other municipalities or with the state.

Primary health care is the priority for all municipalities and should be the main entrance to the health care system. Patients are referred to more complex services (specialised clinics and hospitals) when necessary. The main strategy for primary health care assistance is the Family Health Programme. Each family health team includes at least a doctor, a nurse, a nursing technician and community health agents. Each health service is responsible for a limited territory and its population (maximum of 4000 people per team and 750 people per health agent). In these services the population has access to the ‘basic specialties’: clinical medicine, pediatrics and obstetrics and gynecology. Leprosy control is part of the primary health care. All services should offer (at least) activities of leprosy diagnosis, treatment and contact examination.

Brazil still has approximately 40,000 new leprosy patients diagnosed every year. Like many other countries, leprosy control activities were delivered through vertical and centralised programmes. Decentralisation has been a principle of the Brazilian Health System since the 1980s and is advocated as a strategy for leprosy control.

Betim is a municipality of 345 km² with a population of 407,003 people (2006), and has been important in leprosy control since the opening of Santa Izabel Leprosy Colony in 1930. Leprosy control was centralised until 2001, with only four out of 22 primary health care services developing leprosy activities. In 2001 an effort was made to decentralise these activities to other primary health care services through staff training and supervision. By the end of that year 19 services had trained staff (at least a doctor and a nurse), and 11 of them had managed at least one leprosy patient. In 2002 the Citrolândia Primary Health Care Service was established as the Municipal Reference Centre for Leprosy with the purpose of supporting the decentralisation process through training, supervision and attention to complications. At the time of the study, the Family Health Programme was beginning to be implemented in Betim. Health services were concentrated in fewer health units, and different doctors were responsible for each of the medical specialties available.

This is the second part of a study conducted in 2006 to evaluate the decentralisation process in Betim. The first part is a quantitative study using epidemiological and operational data to compare: (a) pre- and post-decentralisation periods and; (b) the four health services which already had leprosy control activities before 2001, and those which implemented these activities from 2001 onwards. The second part of the study consisted of a focus group discussion with professionals who had participated in the decentralisation process with the objective of identifying: (a) factors which hindered the decentralisation process; (b) factors
which facilitated the decentralisation process; (c) the quality of care after decentralisation. This information would then be used to guide future actions in leprosy control activities in Betim.

**Material and Methods**

A focus group discussion was conducted with health service professionals involved in leprosy control in Betim. The criteria for the composition of the group were to include: (a) professionals who were actively involved in leprosy control (i.e. had received training, were assisting patients, took part in the clinical meetings); (b) professionals from the different kinds of health services involved in leprosy control in Betim (primary care health services, municipal reference centre, ex-leprosy colony); (c) professionals from different professional backgrounds (health service managers, doctors, nurses, occupational therapists and social workers). Of the 12 professionals invited to participate, 10 participated. The group included nine women and one man: three health service managers, two doctors, two nurses, two occupational therapists and one social worker. These professionals represented: eight primary care health services, the municipal reference centre and the ex-leprosy colony. Some of the professionals had experience in more than one type of service (e.g. primary health care service and the municipal reference centre).

The focus group discussion lasted 2 1/2 hours, was recorded on tape and later transcribed. The NVivo7, version 7.0.274.0 (2006) software was used for data analysis. A theme analysis of the content of the discussion was done. The themes were grouped according to the categories included in the topic guide for the focus group discussion: factors which facilitate or hinder the decentralisation process, quality of assistance pre- and post-decentralisation, factors which hinder adequate patient care, work process. Any categories not present in the topic guide but brought up during the discussion were included (e.g. future work).

**Results**

Decentralisation, in general, was evaluated as positive and important to leprosy control in Betim, despite the existing difficulties and the slow moving process.

**Factors which hindered decentralisation**

The group identified the following factors which hindered the decentralisation process in Betim: (a) staff attitude; (b) staff training; (c) stigma; (d) health system organisation and management.

**Staff attitude**

The attitude of professionals who refused to be involved in leprosy control activities greatly hindered the decentralisation process. The group identified lack of confidence despite various

---

1 Clinical meetings were meetings held every month to discuss leprosy and leprosy control. They were open to all professionals. In the first part of the meeting patient cases were presented and discussed. In the second half a topic of interest to the group was presented and discussed.
trainings and the amount of paperwork as the two main reasons usually stated by the professionals who refused to participate in leprosy control activities. These were, however, considered to be excuses which, in reality, hid other reasons such as the unwillingness to take up the workload, availability and commitment which leprosy activities demand. The leprosy patient is considered ‘difficult’ due to the complexity of the disease (reactions and disability). The group noticed, however, that this happens not only with leprosy but also includes other chronic and transmissible diseases. The staff at primary care health services is usually overloaded, as there is an overwhelming demand for medical appointments and the need to attend to so many other ‘causes’. Besides the number of patients to be seen, the characteristics of the patients also contributed to the workload: they are often elderly patients with many co-morbidities and a certain difficulty to make themselves understood. This workload contributes to the resistance of staff in including one more disease and would also make adequate assistance to the leprosy patient more difficult, even when the professional was involved in leprosy activities.

The quality of the relationship between the health professional and the patient also influenced whether patients accepted treatment at a primary care health service. When the staff felt responsible and cared for the patient, he returned after he was referred to another service for an appointment with a specialist. When this relationship was not adequate, the patient went to the reference service and remained there, refusing to go back to his service of origin. Decentralisation would facilitate the establishment of this relationship and the health staff could understand and attend to the patient’s various needs.

The group also considered prejudice and stigma could be present even if not explicitly, as a resistance or indifference to the problem and refusal of involvement with it.

The role of staff from the reference centre could have hindered decentralisation. The group stated they were afraid to let patients be cared for in other primary care services because they were wary of the ability of the recently trained staff to treat patients adequately. This fear no longer exists and the role of the municipal leprosy coordinator was important as she knew the other health services and indicated which were ready to assist leprosy patients encouraging the professionals of the reference centre to refer patients back to these services. Another fear reported by the group was the risk of reference centre staff members being transferred or made redundant due to decrease in work demands. How would one be able to justify the existence of so many professionals in the Reference Centre with the decrease in the number of patients? As the decentralisation process continued the staff realised they would have other functions besides direct patient assistance such as training of other professionals, support in case of difficulties related to diagnosis, identification and treatment of reactions and disabilities.

Staff training

The lack of adequate training of health professionals hindered the decentralisation process. There is a discrepancy between the present assistance model (which theoretically has primary health care as a priority), and the education of health professionals which focuses on specialisation. Professionals who work in primary health care are considered of a lower status, even though the work demands not only comprehensive technical knowledge and experience, but also commitment and responsibility towards patients. The idea that leprosy diagnosis and treatment should be carried out by specialist (dermatologists or leprologists) is still prevalent.
More specifically, the group referred to a lack of knowledge about leprosy, even in those professionals who graduated at public universities which should emphasise the care for diseases which are endemic in our country. This meant leprosy training had to be offered at work and the rotation of professionals demanded constant training.

Stigma

The group considered stigma and prejudice against people with leprosy was still prevalent in the municipality and interfered with decentralisation and patient assistance. Stigma could be an underlying reason for the refusal to work with leprosy activities, but even when this was not the case and leprosy treatment was offered at a defined health post the patient might refuse to get treatment close to his home, where he might be recognised as a leprosy patient in the community. This occasionally happened. The group thought this should be respected and the person should be able to seek treatment in the health service of his choice. Stigma would also make accepting the diagnosis, contact examination and timely diagnosis more difficult as some patients did not tell their families they were being treated. There were also work related difficulties due to the need to hide the diagnosis.

Lack of information regarding leprosy also affected professionals of other areas (e.g. ambulance drivers, janitors, and teachers) who had contact with leprosy patients, and this was not a privilege of professionals from outside the health area. Leprosy patients suffered prejudice or received wrong information regarding the disease when they sought other services of the health system in Betim, such as emergency health services, laboratories, surgeries, or hospitalisation.

Although stigma hindered decentralisation, the group defended that the reduction of stigma could be one of the greatest benefits of decentralisation. Stigma associated to going for treatment at a health service specialised in leprosy is reduced and ‘a disease which can be treated close to home is a disease like any other’.

Assistance model and management

The group discussed the relationship between the assistance model and the difficulty in decentralising leprosy control activities. The group stated that primary health care is a priority only theoretically. In practice, a lot more has been invested in emergency and hospital services. This would make working conditions in primary health care worse and contribute to many professionals leaving primary health care and preferring to work in other kinds of services.

The role of the health service manager was essential for the implementation of leprosy control activities. The staff might not have been willing to take up leprosy control without being ‘convinced’ by the manager. The managers could clearly perceive resistance by the professionals, who were unwilling to participate in trainings, did not want the extra workload and gave priority to specialised knowledge they would also be able to use in their private practices. The manager was responsible for selecting and authorising professionals to take part in trainings, clinical meetings, campaigns. They had to manage situations such as the high rotation of professionals which demanded constant training. Not all managers were aware of the importance of leprosy control which made decentralisation more difficult.
FACTORS WHICH FACILITATED DECENTRALISATION

The factors identified by the group which facilitated decentralisation were: (a) staff training in the Betim; (b) existence of a Municipal Reference Centre.

Staff training in Betim

The group criticised a certain oversimplification of leprosy treatment. Leprosy is said to be a disease which is easy to diagnose and treat, but the group understood it is quite complex. This oversimplification could have increased the fear in professionals who were beginning to work with leprosy. The group stated that they did not feel this in the trainings offered in Betim and they saw this as a positive aspect. During the training they were told there were many patients who might go through treatment with minor complications, but that there would be some complicated patients, with many problems and these could be referred to the municipal reference centre.

The monthly clinical meetings were considered very important for the decentralisation process. At each meeting cases were discussed and a small lecture was given to update professionals on a specific aspect of leprosy. The participation in these meetings increased the confidence of professionals to work with leprosy in their health services even though they could see the complexity of the disease. Besides knowledge, bonds between professionals were gradually formed during the meetings and led to greater cooperation facilitating reference to and from the Municipal Reference Centre.

Existence of a Municipal Reference Centre

The Municipal Reference Centre was considered extremely important in the decentralisation process. The professionals of the primary care health services knew where to refer patients and could discuss cases thus feeling supported in the development of leprosy control. The contact between staff of the reference centre and other services over the telephone or at meetings also generated trust and confidence.

QUALITY OF CARE AFTER DECENTRALISATION

The group considered quality of assistance to have improved after decentralisation. In the health services which already had leprosy control activities the decrease in number of patients would allow better assistance. The group stated that from the perspective of a leprosy specialist, quality of assistance may be considered worse after decentralisation, since the general practitioner would not know about management of leprosy reactions, for example. However, the group considered the quality of assistance would improve as the general practitioner has a more global view of the patient, being more attentive to co-morbidities, infections, complications, drug interactions and side effects, especially of steroids.

Nerve function evaluation is something that needs to be improved in most of the services. Although the staff at the reference centre has more experience in performing the evaluation, decentralisation would make it possible to follow the patient more closely in the primary care health services, as the number of patients would be smaller.
The multidisciplinary approach necessary for adequate management of leprosy patients is salutary for patient care and could improve the quality of health assistance in general if extended to other health actions and programmes.

**Discussion**

Most of the obstacles to decentralisation mentioned in the focus group are not technical or financial but are related to ‘the human face of decentralisation’. The authors mention the significant impact of attitude and motivation of professionals for the implementation and quality of actions stating this may even be more important than financial or material resources. Professionals at health services are fundamental actors, and their perception of the changes resulting from decentralisation of leprosy activities determine whether these actions will be implemented. For this reason, they should be involved in the discussion of guidelines and policies and a clear channel of communication with them should be established.

Along the same line, Merhy presents three types of health care technology: (a) hard (equipment, medication, norms, organisation structure); (b) hard-soft (knowledge); (c) soft (human relations, communication, caring, bonds, attitude, and commitment). He states that what hinders the decentralisation process is the way soft technology is present in the health care work environment. This refers to the relationship established between patient and health care professional where the patient may (or may not) feel welcomed, listened to, accepted and a relationship of trust and hope is built. The professionals who do not wish to take part in leprosy control activities refuse to take up the responsibility and bond which is inherent to care for the leprosy patient. Ideally, this should be present in all health care and the group mentioned that the changes brought about with the implementation of leprosy control should be extended to all other health actions. Merhy advocates that a clear political decision is necessary for the implementation of a health care model guided by the universe of soft technologies. It is impossible to change the attitude of health care professionals unless this is clearly defined in all levels of management.

Soft technology also permeates the inter-professional relationships, where those more experienced take responsibility for the training of the newcomers, welcoming their questions and establishing bonds which will make work easier and more meaningful. Inter-professional relationships also changed with the implementation of leprosy control activities. A ‘leprosy team’ was established in each service, where not only one, but various professionals, from different professional backgrounds are responsible for patient care. This is highly positive and could be extended to all aspects of health care.

The role of the health service manager is essential to the decentralisation and integration of leprosy control activities into basic health care. If the manager is resistant, he may even become the main obstacle to the process. Primary care health services are usually overloaded with the many simultaneous demands: leprosy, STD/AIDS, assistance to adults, children, elderly, women, dental care, mental health, tuberculosis. Responsibilities of different levels are not always clear and planning and implementation of actions of different programmes often occur in a non-articulated way. At the same time, those responsible for the implementation of actions depend on others, over which they have no authority to actually carry out the activities. There needs to be a clear definition of authority, roles and responsibilities in the management of the various actions and in their articulation with basic
health care. These were important issues in the decentralisation process in Betim, where better lines of authority might have prevented some staff from refusing leprosy work.

The reference centre seems to have understood its new role and was extremely important for the decentralisation process. The professionals are responsible for the training held in the municipality. All of the health services have used the reference centre at some time and data from the first part of the study show that the scheduling of patients has been timely (median of 2 days). However, as the data collected refers only to patients who had access to the reference centre, it would be necessary to verify if there are cases which did not have access to the centre and the reasons for this.

In the study of Raju and Dongre 68% of the professionals interviewed thought that the implementation of leprosy control activities would increase the workload and 39% stated this as a reason to oppose decentralisation. The same study mentions the difficulty in hiding the diagnosis in a decentralised context as another obstacle to integration.

Stigma and prejudice are still important obstacles to decentralisation and to care of leprosy patients in the entire health network. In the study of Premkumar et al. prejudice was greater amongst doctors than other professional categories. Hiding the diagnosis makes it more difficult for contact examination and may generate problems such as anxiety, shame and fear. Prejudice is not always clear and exists despite rational knowledge of scientific facts regarding leprosy. Information, either through mass media or training/education, addresses only one of the aspects involved in prejudice and stigma. Another important strategy is advocacy and legislation. Although prejudice reduction is a complex problem, and visible change may take generations, strategies to manage stigma (internal and external factors) have been seen to reduce stigma and improve community participation.

After this study was conducted political changes occurred, and many of the previously trained staff, both clinicians and managers, were substituted. This determined the need for more training. The process of training of primary health care professionals, staff from specialised and emergency services has been started, as well as supervisions and local small-scale campaigns. Already there is a small increase in case detection. For some time now schools, universities and patient’s associations have been invited to leprosy-related events promoted by the State Health Secretariat.

To have a more comprehensive view and evaluation of the decentralisation process in Betim, further studies would be necessary involving people affected by leprosy and health professionals who resisted or refused to implement leprosy control activities.

**Conclusion**

The following conclusions can be drawn from this study:

1. Staff attitude, training, stigma and health system organisation and management were the main factors which hindered the decentralisation of leprosy activities in Betim. Although none of them can be addressed with simple, immediate solutions and all of them demand coordination with partners both within and outside the municipal health secretary, actions have already been started and others have been continued in the hope of improvements in the future.

2. Training of professionals is an ongoing process which can and should be done within the municipality using existent expertise.
A reference service is an important element in the decentralisation process, as a place for training and backup to newly trained professionals. It is important that this service be easily accessed by both professionals and patients.

DISCUSSION GUIDE FOR FOCUS GROUP WITH HEALTH PROFESSIONAL INVOLVED IN LEPROSY CONTROL ACTIVITIES IN BETIM

1. What is your opinion about the process of decentralisation of the leprosy control activities in Betim?
2. Which factors facilitate/hinder the decentralisation process?
3. The first part of this study, showed that there is a difference between health services which were trained to assist people with leprosy (some never implemented leprosy control activities and others did, with more or less quality). What do you attribute this difference to?
4. One of the indicators show there was a decrease in the number of new cases after decentralisation. What do you attribute this to?
5. Compare the assistance to people with leprosy before and after decentralisation (access, diagnosis, follow-up during MDT, contact examination, identification and treatment of reactions, neuritis and disabilities).
6. Which factors facilitate/hinder the assistance to people with leprosy?
7. How can we guarantee the quality of assistance to people with leprosy?
8. What changes in the work process after decentralisation (activities developed, professionals involved, relationship among professionals, relationship with other health services, management)?

Contributorship
Priscila Leiko Fuzikawa (guarantor): conception and design of the study, data collection, analysis and interpretation; drafting the paper.
Francisco de Assis Acúrcio: conception and design of the study, data interpretation, critical revision of the article.
Johan P. Velema: data interpretation and critical revision of the article.
Mariangela Leal Cherchiglia: conception and design of the study, data interpretation, critical revision of the article.

Ethics approval
This study was approved by the Ethical Research Committee of the Federal University of Minas Gerais (ETIC 0013/06).

Details of funding
This study was carried out as part of the Masters Degree Programme of the Faculty of Medicine of the Federal University of Minas Gerais and did not require specific funding.

References
Decentralisation of leprosy control activities in Brazil


6 Criel B, Brouwere V, Dugass S. Integration of vertical programmes in multi-function health services. ITG Press, Antwerp, 1997 (Studies in Health Services Organization and Policy 3).


