An exploration of the views of people with leprosy in Nepal concerning the quality of leprosy services and their impact on adherence behaviour

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Summary Based on a qualitative interview study conducted in eastern Nepal, this paper explores the quality of services received by people with leprosy and the impact of quality of services received on adherence behaviour. The study found that a person’s status within the family and community influenced the quality of care, which in turn affected adherence to treatment. Five major types of deficiency in the quality of care experienced were identified, particularly by the poor people and by women. These were the attitude and behaviour of the health worker, the practitioner-centeredness of the care and lack of information sharing, the organization of the health services, barriers in accessibility of the leprosy services, and lack of, or carelessness in, patient referral. This paper explores these types of deficiencies and the way people affected by leprosy cope with them. People of a higher status had access to enabling factors which allowed them to continue treatment, people of a lower status had to endure many disadvantages which had a great influence on their adherence behaviour.

Introduction

Quality of care is multi-dimensional and thus its assessment requires measurement along each different dimension. According to Donabedian,\(^1\) quality has at least two components: technical quality of care and interpersonal interaction. Quality of technical care is the extent to which the care provided is expected to achieve the most favourable balance of risks and benefits to the patient. Achieving this balance can be the responsibility of the practitioner solely, or it can be a joint responsibility of the patient and the practitioner, whereby the patients place their own values on the expected benefits and risks. The management of the interpersonal relationship must meet socially defined values and norms that govern the interaction of individuals in general, and also in the particular context of health service delivery. These norms are reinforced in part by the ethical dicta of health professions, and by the expectations and aspirations of individual patients. The degree of quality is measured by the extent of conformity to these values, norms, expectations, and aspirations.\(^1\) DiPrete Brown et al.\(^2\) have a wider definition of quality, and their dimensions were developed and

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used in developing countries. These dimensions are effectiveness, efficiency, accessibility, scientific–technical quality (including technical competence, interpersonal relations, continuity, and safety), and amenities (e.g., comfort, cleanliness, privacy, educational videos). Considering the services in developing countries, DiPrete Brown et al. consider not only geographic and economic accessibility, but also other types of accessibility like social or cultural (the acceptability within the context of the patient’s cultural values, beliefs and attitudes); organizational (convenience of services: clinic opening hours, appointment systems, waiting time); and linguistic barriers (availability of services in the local language).

Studies into patients’ views of services show that people find some dimensions of care more important than other dimensions. A study in Guinea identified and classified criteria that the public uses to judge the quality of primary health care. The users appeared very sensitive to aspects of the interpersonal relations they had with professionals and the technical quality of the care provided. They recognized the importance of a good diagnosis, adequate treatment, as well as the need to receive sufficient information on the health problem and the treatment to follow. Another international comparative study into the quality of vaccination services looked at the perception and experiences of users with the care provided. They found that users devoted a great deal of effort to having their children vaccinated, despite the impolite behaviour of the vaccinators, and the distance to services. Technically competent vaccinators were not perceived as such if they lacked social skills. The occurrence of side-effects and the perceived low quality of vaccination practice caused users to stop visiting vaccination clinics.

Kols and Sherman argued that patient satisfaction is not an adequate measure of quality in developing countries, because satisfaction with the services does not have to reflect the quality of those services, but may mean that expectations are low. In addition, expectations of users can differ from what is expected to be good quality of services from the provider’s perspective. Patients have a limited understanding of medical science and technology and can therefore demand things the practitioner cannot give, or are not found competent to access the technical quality of care and base their satisfaction on the practitioner’s personality and the interpersonal relationship.

The literature described above shows that individuals evaluate the different dimensions of care in their own way and decide on the basis of this evaluation whether they want to continue their treatment or not. For each individual, a different combination of dimensions is important in this decision, and this evaluation can be very different, as expected, from a provider’s perspective. It is important to understand the meaning that the different dimensions of quality of care have for the individuals in order to understand (dis)continuation of treatment and use of services.

The research described in this paper, therefore, was shaped by a number of aims:

- Understanding why people after first seeking help at the health post decide to discontinue their treatment at a later stage (this article reflects themes that emerged from a larger study aimed at understanding adherence to leprosy treatment).
- Exploration of people’s experiences with the leprosy services provided and the different meanings of quality of care.
- Exploration of how the care experienced could contribute to discontinuation of treatment.
Materials and methods

In order to understand the complex nature of both non-adherence and quality of care a qualitative approach was chosen. Using a qualitative approach allowed the researcher to ‘see through the eyes’ of the interviewees and explore their subjective experience with leprosy, its treatment and the services provided. People have their own perception and understanding of their disease and its treatment and act upon this understanding.

Seventy-six people were interviewed in depth about their experiences with the leprosy services. They all were registered as MB patients at general government health posts situated in the project area of the Eastern Leprosy Control Project (ELCP) in Nepal. They had begun their treatment no longer than four years before the start of the fieldwork. The research was conducted between 1998–2002. A random sampling technique was used to select people for interviewing. Approval had been received from the National Research Counsel of Nepal. After some pre-testing, an interview guide was used. In relation to the experienced quality of care the following themes were explored: people’s reaction after they were informed they had leprosy; experience with treatment, this included problems and side-effects, episodes of acute physical problems, problems in attending (financial, physical), experienced quality of care; and if people were registered as being defaulters, their reasons for stopping treatment. A person was called a defaulter if he or she had missed 12 visits to the health post. People were interviewed in their homes, after verbal informed consent was gained. Interviews lasted for 1.5–2 h and were tape recorded. The recordings were translated and transcribed and were analysed by using a grounded theory approach,10 cognitive mapping technique, and the pattern matching methodology as describe by Yin.11 In total, 29 people who discontinued treatment (they had taken between one and 22 months of MDT treatment) and 47 people who had completed their treatment (RFTs) were interviewed. A good distribution existed between those who lived in rural and urban areas, and those belonging to the different tribes and religions in the area. More men than women were interviewed. More detail about the method and sample is available elsewhere.7 This study is a qualitative study and in doing so I try to develop a framework of understanding, in which not the individual pieces of data are important, but the whole picture the data form together. To show commonalities and deviant cases and to differentiate between different groups I have used the words ‘few’ to indicate when only a few interviewees shared a particular opinion (<10), ‘some’ when around half did so, and ‘many’ when a majority opinion was described (>2/3).

SOME BACKGROUND INFORMATION ON NEPAL

Officially, Nepal is a Hindu Kingdom, but it includes Buddhist, Muslim, and Christian minorities. In 2004, the literacy rate was estimated to be 62.7% among the males and 27.6% among females.12 As Nepal is a Hindu society, social relationships are influenced by religious or ritual norms and values, but also by economic and political hierarchies. In the past, the ritual hierarchy was the same as those defined by economic and political power. This has however changed. A person of a high ritual status does not automatically possess a high economic and political status any longer. The three different types of hierarchy are however very much interrelated. As a person’s status depends on the many different roles and powers the person has in his or her family and in his or her community, it is not possible to talk about the status of a person. It also depends on different contexts and situations.
Results

Although the majority of the interviewees believed in the effectiveness of the medicines, they faced many problems at the health post, which made it very difficult for some to complete treatment. Social differentiation was important in the way people experienced the leprosy services and consequently coped with these experiences. The study showed that the socio-cultural environment in which the person affected by leprosy lives has an impact on the quality of care experienced and on adherence to treatment. The relationships between patients and health professionals in Nepal were affected by their relative positions in the different hierarchies, and the status in the family and community of the person with leprosy. How this worked was a complex process. In this study, I differentiate between people with a higher and lower status, how I categorized the interviewees is explained in the Appendix.

Five major types of deficiency in the quality of care experienced were identified in this study. These were the attitude and behaviour of the health worker, the practitioner-centeredness of the care and lack of information sharing, the organization of the health services, barriers in accessibility of the leprosy services, and lack of, or carelessness in, patient referral. Experiences that were reported most frequently during the interviews were related to the attitude and behaviour of the health worker and the organization of the health services. The following sections describe these in more detail, how people dealt with these and how their ability to maintain treatment was affected. Throughout the sections the influence of status on people’s experiences with the leprosy services is demonstrated.

Coping Strategies in Managing the Behaviour of the Health Worker

The results of the analysis shows variations in the attitude and behaviour of the health worker towards persons affected by leprosy, which resulted in different coping strategies being employed by those with different status. The attitude and behaviour of the health worker was supportive towards people of a higher status in the community. People of a higher status, and those who lived near the health post, were less likely to be scolded, received more information and empathy, and in some cases the treatment was provided in secret at the health post, or the medicines were delivered to their homes. Many people of a higher status within the community stated that the health worker had helped them, and that the care received had been satisfactory. In contrast, many people of a lower status in the community said that they had observed or experienced the health worker treating them or others like them in a negative way. They reported that they were scolded when they asked questions, came late, had missed one or more monthly visits, or had requested more or additional medicines. Out of fear that the health worker would scold them when they came late, some tried to arrive on time. A few people were so afraid of being scolded by the health worker that they did not return, and consequently discontinued treatment. The majority, however, had decided to endure the bad treatment to ensure their supply of medicines. The differences in the attitude and behaviour of the health workers towards people of different status reflected the general way people deal with each other in Nepal. People of a higher status can make decisions independently. People in a lower position were also generally unable to question decisions made by those in a higher position. Some of the affected people who held a higher position in the community often described the health worker as a friend, relative, schoolmate, or as a person who helped them. The manner in which they discussed the behaviour of the health workers demonstrated that the health workers were in a similar position to themselves. The narratives that people with a
lower community status related described a health worker who communicated very little; someone who was in a hurry and who often became irritated; someone whose behaviour they had to accept if they wanted to be cured. Health workers were regarded as people who were in control, and had control over the treatment. In addition they were mostly men and thus, according to gender relations in Nepal, were superior to women.

Differences in the attitude and behaviour of the health worker influenced people’s adherence to treatment. Half of the RFTs or their family members held a higher position within the community and the effects that this had on the behaviour of the health worker acted as factor enabling completion of their treatment. One example of this was being able to demand services from the health worker, which allowed them to continue treatment without incurring too many problems at the health post. In contrast, many people of a lower status within the community were scolded by the health worker, and for some this resulted in discontinuation of treatment.

COPING STRATEGIES IN MANAGING PRACTITIONER-CENTRED CARE AND LACK OF INFORMATION SHARING

The care delivered was very practitioner-centred; the expectations of the health worker were the starting point of treatment. The aim of the health worker was that people had to visit the health post for 24 months (at the time of the fieldwork, the treatment recommendation for MB leprosy was 24 months of treatment to be completed within 36 months). The communication was one-way; in which the health worker decided on the information given. Sharing of information and experiences was not often done. The consequence of this one-way communication was that the health worker did not check people’s beliefs and knowledge about leprosy.

The majority of the interviewees stated that they had hardly received any information. In cases where they received information, this mainly concerned the duration of treatment and the statement that the disease was curable. An acceptable explanation of what the health worker meant by cure was not given, and the expectations of the persons affected were not checked, which resulted in them believing that they had to continue treatment as long as symptoms remained. None of the patients had been informed about the possibility of developing side-effects. For the interviewees who had developed side-effects, these came as a surprise. The consequences of this were that some people discontinued treatment, and others sought treatment somewhere else. The lack of information on means of transmission of leprosy resulted in people fearing transmitting their disease to others, or others fearing being infected by a person affected by leprosy. The consequences of this were unnecessary restrictions within family and community life. On the few occasions that some people reported other information being given by the health worker, this concerned their diet, protection of numb areas, and advice about concealment.

During their treatment some patients expected to be examined on each visit and definitely at the end of the full course of treatment. Many reported that often the health worker would hand out the medicines or discharge them from treatment, after only a glance at the register. This gave the affected person the impression that the health worker did not know which stage their disease was at and consequently people doubted the technical competence of the health worker. This does not mean, however, that the actual examination was inadequate by medical standards. On other occasions, the experiences reported by the people with leprosy showed that the technical competence of the health worker had not been adequate. Some stated that
they were first told to take 24 months medication and had then been told that they had been cured before the completion of the 24th dose of the treatment. This would imply that the doctor did not look in the register or was not aware of the duration of treatment, and had thus, possibly unintentionally, denied treatment to them.

The attitude of the health worker did not allow people to discuss expectations regarding the amenities at the health post, like privacy. In the majority of health posts in Nepal, either other people are waiting to see the health worker in the same examination room, or the doors to the room are open and everybody in the corridor can hear what is happening. This makes it especially difficult for women to be examined, and to ask the health worker questions about specific female problems. As people feared exposure of their disease to other community members, some people perceived the lack of privacy at the health post as a trigger for exposure. People who reported this were of a higher community status, but people of a higher community status could demand alternative methods of medication collection. Other people had to accept the lack of privacy.

COPING STRATEGIES IN MANAGING THE ORGANIZATION OF THE HEALTH POST

While discussing their experiences of the delivery of the leprosy services, most people reported unsatisfactory aspects related to the organization of the leprosy services and especially the (unnecessarily) strict rules and regulations of the health post. The rules and regulations mentioned were restricted opening hours, the necessity of showing their patient identification card for the collection of MDT medicines, and the ‘proxy’ policy. During the time of the fieldwork, the leprosy services at the health posts were provided only once a month and in many cases not for the entire day. The interviewees described how they often were unable to get the medicines when they arrived late or on the wrong day. If people missed a month of treatment they were considered as irregular patients, and often were blamed for not being motivated to complete treatment. After arriving at the health post, the interviewees had to show their patient identification card, and only then could they obtain the medicines. With some, these cards got lost or damaged. After they had lost this card, some patients were even refused treatment. When those affected by leprosy were too busy to collect the medicines or in case of illness, they were permitted to send somebody else to collect them on their behalf. Because the health workers prefer to see the patients personally, this (proxy) policy is not promoted. The policy is not to refuse the medicines to the person who comes to collect them for a patient, but to supply and to emphasize the importance for the patient to come and personally collect the medicines. The manner in which this proxy policy had been implemented at some health posts, however, had the unintended effect of discouraging adherence.

Other aspects of the organization of the health post that were perceived as problematic were the regular absence of the health worker and medicines. It could happen that the health worker was not present, sometimes even for several consecutive visits. For some interviewees, going back in vain over several consecutive visits was the reason for discontinuing their treatment. Another problem was the long waiting times at the health posts. The busy and time-restricted clinic days, as well as the health worker coming late, caused long waiting times. Some interviewees reported that collecting the medicines from the health post took them a whole day, a day in which they were unable to earn money.

Some people in a higher position could bypass the rules and regulations at the clinic, enabling them to visit the health post after closing hours, avoid the queues, and have
medicines brought to their homes. People of a lower status in the community could not bypass these rules and consequently had to accept them.

The way leprosy services are organized had an influence on adherence to treatment. One out of three people who had defaulted had not made this decision themselves: the health worker had denied treatment to them. They had been ‘forced’ to default, because they arrived late, had lost their patient identification card, or had sent a family member to collect the medicines. As discussed above people felt they had to accept the health worker’s refusal to distribute the medicines to them.

COPING STRATEGIES IN MANAGING BARRIERS IN ACCESSING THE HEALTH POST

The third type of deficiency in quality of care was that of lack of accessibility to services. The interviewees reported several barriers to reaching the health posts and obtaining medicines. Some of those barriers were related to the distance to the health post and the physical barriers to getting there. In the eastern Terai of Nepal, there are numerous health posts, but the distance between them can be up to 30 km. This entails people having to travel long distances. For others, the distance may have been shorter, but natural barriers like rivers or heavy rain during the monsoons, made travelling difficult. For people with wounds, or suffering from illness, the long distance to the health post was a burden. Those with wounds attempted to get there as best they could. Some who had become very ill decided to stay at home and had sent a family member on their behalf.

Not only geographical barriers, but also economic barriers such as the cost of public transport, or the health post fees, were mentioned. Others stated that due to the distance or the long waiting times at the clinic they had lost a day’s income. Some were day labourers and they had to search for work on a daily basis, hence the loss of a day’s income. Some women said that they depended on others to accompany them and that they had to find a relative who was willing to help them on a monthly basis. For some women, this dependency on others made it for some difficult to continue treatment.

A few people reported that they had to pay a small bribe in order to get the medicines. Some of them had to pay the 2 rupee registration fee at every visit (and not only at the time of registration), others reported extra and unnecessary costly medical tests, and a few reported that they had to give the health worker something (more money or food) before the medicines was given to them.

Problems in accessing the health post did not, however, influence their intention to continue treatment. People feared the social consequences of their disease and devoted a great deal of effort to reaching the health post.

COPING STRATEGIES IN MANAGING LACK OF AND CARELESSNESS IN PATIENT REFERRAL

After people regarded their symptoms as severe enough to seek medical care, or after being advised by others to seek care, people went to different places for help, to private doctors or to traditional healers. By the time they arrived at the health post, they had already spent a considerable amount of money, had been diagnosed at each place, and had received different types of treatment. In most cases, they were not referred to the health post and came after receiving advice from friends and other community members.
After leprosy had been diagnosed at the health post, the majority of the interviewees collected their medicines on a regular basis. Sometimes they were referred to larger or specialized clinics and hospitals. A few people were not able to afford to travel to these places, others went as referred, but were refused treatment as they had not been given their medical file, or a referral letter. Without these, they were refused care and then referred back to their original health post.

Conclusions

The contribution of this study to former studies on the quality of care of the services delivered at health posts is that it demonstrates how the social differentiation affected the quality of the services, the experiences of patients with these services and their adherence behaviour. Leprosy care is provided through the relationship between health worker and a person affected by leprosy, and this relationship is based on the general social rules and norms. Where the status of the affected people was similar to that of the health worker, they could regard the health worker as their peer and could negotiate the manner in which the treatment was received. People of a higher community status had no complaints about the relationship with the health worker, and had very few complaints about the organization of the clinics. Some of these people could even demand special services from the health worker. The supportive attitude of the health worker and, for them, less strict rules and regulations at the health posts, acted as factors that enabled to complete treatment. By contrast, many of the persons affected by leprosy who were of a lower status within the family or community reported that they had to accept the behaviour of the health worker and the organization of the clinic (the strict rules and regulations). The majority explained that they had no means of arguing against the behaviour of the health worker, but had to accept it and to act submissively on the next visit. If they did ask questions, the behaviour of the health worker was punitive. Some people have to accept what happens at the health post and have no control over it. For some the only control they perceived they had was to stop going to the health post as this would stop the negative behaviour of the health worker towards them. A kind of impasse was created in which they had either to endure the negative behaviour of the health worker patiently and complete their treatment, or to stop the confrontation by discontinuing treatment.

This study demonstrates that the health worker even had the power to refuse treatment to people who they thought were ignorant, or not motivated. This study demonstrated that they were expected to comply with treatment and with the rules and regulations of the health post, as they had to comply with all rules and regulations they had learned throughout their lives. I specifically use the term ‘comply’ here and not ‘adherence’. The term ‘compliance’ refers to a difference in power, whereby the person with less power has to obey the rules and regulations as set by others. The health workers had informed them about the fact that they had to come back every month. If the person did not do this they were scolded and blamed for not obeying the ‘rules’. When asked how the services could be improved, many suggested that it was important that the health worker was present and medicines were available. A few suggested that the behaviour of the health worker had to change. In addition, this indicates that the attitude of the health worker, although people regard it as very negative, fits in with what they expect.
Health workers regarded people of a higher status as their peers. At the same time however, they differentiated themselves from them in relation to their medical expertise. Although people of a higher status could negotiate the way care was delivered to them, they could not negotiate the content of this care and the information provided to them. This showed that the care delivered was very much practitioner-centred, and that the health worker had the technical expertise to define a treatment regimen, which the patient had to comply with. As the affected person had no technical medical knowledge, the health worker was in a powerful position over the patient. In this practitioner-centred care, the expectations of the health worker are the starting point of treatment and the aim in this view is that people have to visit the health post for 24 months.

The data on quality of care provide an image of a health worker who is working hard to cure leprosy, but who is mostly indifferent to the lives the patients have outside the clinics. It further shows that people affected by leprosy spend a great deal of effort in dealing with their experiences with the leprosy services. It was their strong motivation to cure their disease that was the mainspring behind their regular visits to the health posts and that made it possible to endure many disadvantages with regard to the quality of services provided.

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References

Appendix: Status within the community and family

DIFFERENT FACTORS DETERMINING A PERSON’S COMMUNITY STATUS

- **Land ownership and size of the land.** This was about what the person affected described concerning income received from the land, and whether its produce was sufficient to live on for a whole year, without the need for supplementary paid work.

- **Occupation: type of occupation of all family members.** I used the categories developed by Rao. He defined nine categories for occupation: landless labour, share cropper, land owner, employ others on land, non-agricultural service, artisan, owner of an industry, other occupations, and unemployed.

- **Educational level of the patient or other family members.** For some affected persons interviewed, it was very important to mention that they could read. The ability to read gave them a certain status or position within the community.

- **Type of family: being a nuclear or joint family, and type of family structure.** Some joint families were those that had lived in the community for many generations. This and the presence of several married brothers gave the family a higher status.

- **Type of housing the family had.** It made a difference if the family lived in a wooden, two-storey house or in a hut made of mud or straw.

- **Political status.** Some people stated that they were active members of a political party. Being an active member of a political party means that people can influence some decisions regarding the whole village, such as planning of roads, taxes, etc.

- **Ritual status.** Some people were traditional healers, or were Brahmin priests, which gave them a higher status.

Different cross-cutting factors acted together to give rise to family status within the community. If for example, a person was a landowner, I categorized this person as being of higher status. If a person lived in a mud hut, was a day labourer and mentioned that he or she had days without income and thus food, I categorized this person as having a lower status. Active members of a political party, or people with a ritual status, or shopkeepers, were mostly categorized as higher status, though not all factors were congruent. The results of this exercise revealed that people with a higher status had more control over their lives. These interviewees mentioned that because of their status people could not ask them questions about their disease, or who because of their status could demand services from the health worker. Other people had a lower status, and they believed they had no control and had to accept the behaviour of others towards them. Deciding if an interviewee had a higher or lower status was carried out carefully and checked for all the factors involved. It was found that four defaulters and 23 RFTs had a higher or even very high status within the community, and 25 defaulter and 24 RFTs had a lower status. This shows that although people were very motivated to complete their treatment, only half of the people of a lower status managed to continue their leprosy treatment.

Within the family, different hierarchies were identified, based on decision-making power, gender, and age. Within these, a further distinction was observed between the people who could contribute to the family income, and those who could not.