ORIGINAL RESEARCH

QUALITY OF LIFE, PERCEIVED STIGMA, ACTIVITY AND PARTICIPATION OF PEOPLE WITH LEPROSY-RELATED DISABILITIES IN SOUTH-EAST NEPAL

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ABSTRACT

In Nepal, many people live with leprosy-related disabilities. The objective of this study was to evaluate differences in socio-economic characteristics, quality of life (QOL), perceived stigma, activity and participation among people affected by leprosy as a group and between this group and the general population, and to identify prime determinants of QOL among the leprosy-affected people.

People with leprosy-related disabilities (N=100; 54DGI/46DGII) and community controls (N=100) were selected from Morang district, South-East Nepal, using quota sampling. QOL, perceived stigma and participation and activity limitations were measured using the Nepali abbreviated version of the World Health Organisation Quality of Life (WHOQOL) assessment and the Nepali versions of the Jacoby Scale, Participation Scale and Green Pastures Activity Scale (GPAS), respectively.

Total QOL, participation and activity levels of people affected by leprosy were worse than those of the general population. Regression analysis showed that the ability to maintain a family, satisfaction with health, vocational training, sex, activity and participation limitations (the latter for QOL only), perceived stigma and living situation (i.e. joint family, type of house) were significantly associated with a deterioration in QOL and higher participation restriction in one or both of the grading groups.

There is an urgent need for interventions focused on quick referral of people with leprosy, to minimize the development of visible impairments, and social rehabilitation. The latter can be achieved by creating more public awareness, providing (financial) support for income generating projects and /or vocational training to leprosy- affected people, and by encouraging them to be involved in all community development activities. The current results indicate that such measures would help improve the quality of life of people with leprosy-related disabilities.

Key words: Leprosy, disability, quality of life, perceived stigma, activity, participation, Nepal

INTRODUCTION

Leprosy or Hansen's disease is an infectious disease, caused by a bacteria called Mycobacterium leprae, which has affected humanity for centuries in many parts of the world. Today, leprosy can be cured relatively easily, yet its effects on a person's life can carry on indefinitely due to the permanent and progressive physical disability it can create (1). Usually, the visible impairments are not a direct result of the infection, but are caused by injuries to limbs that have become anaesthetised due to peripheral nerve damage. Such limbs are susceptible to further damage and secondary infection that may even necessitate amputation (1). Leprosy related disability is categorised in Disability Grade I (DGI) and Disability Grade II (DGII). Grade I disabilities include anaesthetic hands or feet; people with Grade II have visible impairments. If people with Grade I disability do not protect themselves in time, Grade II disability such as chronic ulcers, contractures and bone loss may occur (2).

Besides the physical aspects, leprosy and leprosy-related disabilities may predispose people to developing psychological, economic and social problems, which have an adverse effect on quality of life (QOL). However, the number of studies that have examined these issues is scarce. Two former studies, performed in India and Bangladesh, indicated that people with leprosy – especially those with DGII – had a significantly lower QOL compared to people from the general population (3, 4). Women seemed to have better QOL in each domain and age group than men. These studies also revealed that economic status and QOL scores were positively correlated. In addition, factors that contribute to a deteriorated QOL among people affected by leprosy appeared to be fewer years of education, the presence of Grade II disabilities, a lower annual income and perceived stigma. According to Tsutsumi et al (2005), there is also a direct relationship between stigma perceived by people affected by leprosy and severe states of depression (5). Only one study, conducted in China, focused mainly on the social constraints and showed that people affected by leprosy were often isolated from the community, were living alone, and had difficulty with self care, daily activities, productive ability and social participation (6).

In Nepal, the elimination of leprosy as a public health problem was achieved in December 2009, and the current prevalence rate is 0.89/10,000 (7). However, for decades Nepal was one of the most leprosy-endemic countries in the world and as a result, there are still many people with leprosy-related disabilities, who suffer from social exclusion and place a demand on health and other services (8).

During the Nepali fiscal year 2007/2008, 1,282 persons were newly detected and diagnosed in East Nepal which is 28.6% of all cases in the country (4,483) (9). Reliable recent estimates are not available on the number of people in Nepal who have leprosy-related disabilities, or of people with disabilities in general. One of the few studies done on people with leprosy-related disabilities in the South-East area of Nepal showed that people with visible impairments face difficulties in participating in social activities and performing daily activities (1). Moreover, insufficient health care and a lack of moral and technical support from society appeared to inflict significant constraints on the lives of people affected by leprosy (1). The results of the study indicated that there is a need for studies on QOL - and the relationship with activity and participation - in this region of Nepal.

AIM

Therefore, this study aims to (a) assess the QOL of people with leprosy-related disabilities (separate for people with DGI and DGII) compared to the general population, (b) evaluate the relationship between QOL, perceived stigma, activity and participation restriction and (c) evaluate which other factors, including socio-demographic and socio-economic characteristics, are associated with the QOL of people with leprosy related disabilities in this area. In doing so, the authors will establish the impact of leprosy- related disabilities on the prime aspects in life and suggest key interventions which will help to change the lives of people affected by leprosy, in the future.

METHOD

Study design

The study was (comparative) cross-sectional in its design.

Study population and study sample

The study population comprised leprosy-affected people with DG I and DG II in Eastern Nepal. Both the cases and controls were selected from urban, rural and slum communities in Morang , using quota sampling. The sampling was initiated by first collecting information on the number and addresses of leprosy-affected people in each village development committee (VDC). Subsequently, leprosy-affected people were selected based on disability grade, gender and caste at the VDCs with the highest number of registered leprosy-affected people in the closest vicinity of Biratnagar. Both the people with leprosy-related disabilities and controls were between the ages of 15-65, representing the economically active age group in Nepal. To be able to compare the QOL between the leprosy-affected people and controls, an attempt was made to randomly select controls representing the same overall male/female-ratio, age groups and castes as the people affected by leprosy found in Morang district, because these factors were likely to act as confounding factors influencing QOL in the study area.

The total number of registered leprosy cases in Morang district was 2,114 in the last five years. This number included 124 DGI and 87 DGII cases. To detect a significant difference in QOL scores between people affected by leprosy and community controls (with a CI=10 and confidence level=95%) 54 DGI and 46 DGII cases were selected for the study to obtain sufficient statistical power. Data on the participants were obtained from the Leprosy Referral Clinic in Biratnagar, after obtaining their consent. The total population of Morang district was 999877(9). From this population 100 controls were selected. Controls with a history of leprosy, chronic diseases or other disabilities were excluded.

Instruments

A questionnaire was developed containing questions on socio-economic and socio-demographic characteristics, to obtain information about the location of the residence, ethnicity, caste, age, sex, study opportunity, vocational training, educational level, profession or occupation, marital status, income, ability to maintain family (in months), family situation (joint/separate), quality of housing and treatment status.

In addition, the WHOQOL-BREF was used. The WHOQOL-BREF was developed to evaluate QOL, and contains 26 items divided into four domains: physical, psychological, social relationships and environmental. The first two questions of the WHOQOL-BREF give an overall grade on their perception of life (Q1) and health (Q2). Each item uses a 5-point response scale, with higher scores denoting a higher QOL (10, 11). The validity and reliability of the Nepali version of the WHOQOL-BREF had been previously confirmed (12).

The Jacoby scale was used to measure perceived stigma. This instrument contains 3 items, each of which uses a 0 (No) or 1 (Yes) response. Measuring perceived stigma is subjective - it reflects the way people with a certain condition/disability perceive themselves as being stigmatised. It is different from enacted stigma, which is related to social attitudes and behaviors (5, 13).

Activity and participation assessment were measured using the Green Pastures Activity Scale (GPAS) and Participation Scale, respectively. The GPAS was developed to assess a wide range of activities of daily living relevant in low and middle-income countries (14, 15). It was developed as a generic instrument for use under circumstances that prevail in Nepal. The GPAS was validated in Nepal by the International Nepal Fellowship in a former survey (14). The Participation Scale was developed and validated simultaneously in seven languages in low and middle-income countries like India, Nepal and Brazil (15, 16). The scale is generic and is particularly suitable for use among people affected by stigmatised conditions, such as leprosy and HIV/AIDS. It has been used for many purposes, including evaluation of the impact of a stigma reduction project and to study risk factors for participation restrictions (15, 16). Other programmes are using the instrument in ongoing rehabilitation services to help select people for services, to monitor progress and to evaluate the impact of interventions at the individual level. In both the GPAS and Participation scale, higher scores denote a more severe limitation or restriction in activity and participation (15, 16).

The services of one interviewer who had experience in the field of public health, was used for data collection. The persons affected by leprosy were found with the help of Netherlands Leprosy Relief and the Leprosy Referral Center in Biratnagar. All questionnaires were interview-based due to the high illiteracy rate in the area. After preliminary data-analysis, a focus group discussion was held, in the Leprosy Referral Center in Biratnagar, to triangulate the findings from the questionnaires and to collect more detailed information about the individual domains of the WHOQOL-BREF. Especially, the social and environmental aspects of the issues concerning people with leprosy-related disabilities were discussed, since the characteristic cultural customs, attitudinal environment and facilitating environment of this study sample are most complicated to grasp by statistical analysis. The focus group included 9 persons, mixed sexes and mixed disability grades, all between the ages of 15-65.

Data analysis

Descriptive statistics were used to describe the basic features of the data, for example mean, standard deviation, etc. Differences in socio-demographic variable frequencies are calculated using the Chi-square ($\chi 2$)-test for multiple independent samples. Total WHOQOL-BREF scores and subdomain scores are compared between groups, by analysis of variance (ANOVA). The difference in mean GPAS, Participation Scale and Jacoby scores are calculated with the Mann-Whitney U test, since these scores were not normally distributed. Owing to an indication of interaction between severity of impairment and sex, all analyses were performed separately for disability grade. Multiple regression analysis of the people with leprosy-related disabilities using WHOQOL-BREF total scores (linear) and participation scores (quantile) as a dependent variable was employed, using SAS 11.0 to examine the magnitude of impact of each factor (e.g. age, sex, caste, marital status, presence of perceived stigma, quality of housing, income, occupation, study opportunity, ability to maintain family, parent situation and GPAS score).

RESULTS

Socio-demographic characteristics

Because the controls represented the same caste and age groups as the experimental group, no significant differences in caste (p=0.63 and p=0.99 for men and women, respectively) and age (p=0.80 and p=0.27 for men and women, respectively) were identified between the groups for either sex. Marital status, vocational training and type of home were not significantly different between the sexes either. The socio-demographic variables that did show notable differences between the three groups (DGI, DGII and controls) were educational level, occupational status and income per month (Table 1). The educational level was divided as literate and illiterate, in which the precondition for literacy was the ability to read and write. In the female group there was a significant difference in educational level between the groups (p=0.02), while no such difference was found in the male group. The main occupations for both leprosy-affected people and controls were agriculture-related jobs and running a business. Within both sex groups there was a significant difference between people affected by leprosy, and controls with regard to employment (p<0.001 and p<0.001) and income per month (p=0.025 and p=0.003, respectively), caused especially by the unemployment and low incomes of the people with visible impairment.

WHOQOL-BREF, participation and activity scores of cases and controls.

Table 2 shows that the WHOQOL-BREF total and sub-domain scores among the cases were significantly lower compared to the controls (p<0.001 for all scores, except for the social relationship domain). Moreover, the GPAS and Participation scale showed significantly higher mean scores for the cases than the controls (p<0.001 for both scales).

WHOQOL-BREF, activity, participation and perceived stigma scores of people with leprosy-related disabilities.

Differences in QOL-BREF total and sub-domain scores , and in participation and activity scores between affected people with DGI and DGII are shown in Table 3. Total WHOQOL-BREF scores were lower for DGII cases than for DGI cases, though not significantly so (p=0.14). The physical (p=0.01) and psychological (p=0.02) QOL domains, as well as the GPAS, Participation and Jacoby scale did show a significant difference between DGI and DGII people affected by leprosy. Overall, women appeared to have a lower QOL and higher participation restriction and perceived stigma compared to men. In the DGI group, women showed significantly lower scores on total WHOQOL-BREF scores, and the psychological and social QOL domain (p<0.05). In the DGII group only the Participation score was significantly higher in women compared to men with visible impairments, indicating a higher participation restriction (p=0.03).

The relationship between the WHOQOL-BREF, activity, participation and perceived stigma scores of people with leprosy-related disabilities.

A significant univariate association between the GPAS (p=0.003) and the Jacoby scale (p<0.001) was found in relation to the Participation scale scores. Similarly, significant univariate associations were observed between the GPAS and the Jacoby scale (both p<0.001) in relation to the QOL scores.

Multiple regression analysis of WHOQOL-BREF and Participation scores.

To explore the factors contributing to a deterioration of WHOQOL-BREF and Participation scores of the people affected by leprosy, linear and quantile multiple regression analysis was performed (Table 4 and 5). Outcomes are reported separately for disability grade. In the DGI group of people, the inability to maintain the family, a lower satisfaction with health, higher GPAS activity scores and the absence of vocational training possibilities were significantly associated with a deterioration in QOL scores (p<0.001, p<0.001, p=0.042, p<0.001, respectively). Moreover, in the DGII group, the inability to maintain the family, a lower satisfaction with health and higher Participation scores show a significant correlation with lower QOL scores (p=0.008, p=0.005, p=0.002, respectively). Factors significantly associated with higher Participation scores in the DGI group were female sex and higher GPAS activity scores (p=0.008 and p<0.001). For the DGII group, these factors were female sex, joint families, higher stigma and higher GPAS activity scores (p=0.008, p=0.033, p<0.001, p=0.001, respectively).

Focus group discussion

During the focus group discussion, the people with leprosy-related disabilities expressed that as a result of the lower educational and working opportunities, they are deprived of a 'normal' working life and disadvantaged when it comes to income generation and availability of services. According to them, this also results in a lower awareness which prevents them from seeking help for their (physical) problems sooner. The leprosy- affected people in the focus group who had an occupation, were mostly involved in agricultural work and their contribution to the work was not perceived as less compared to other family members.

In addition, their social life is highly affected since they are frequently not allowed to participate in community activities and festivals, and are unable to work or marry, leading to insecurity, shame, isolation and consequent economic loss. Most of the people with visible impairments in the focus group could not accept their bodily appearance, which led to anxiety, despair and depressive feelings. Almost all the people affected by leprosy expressed that they and their family/ community believe that the disease was inflicted on them as a punishment, and therefore they are often seen as 'sinners'. Due to these reasons, they reported that people with leprosy-related disabilities often choose to leave their families to get treated for leprosy in another district, so that their families are not burdened by their disease.

Concerning the environmental aspect, the people in the focus group reported that due to a lack of modifications (e.g. furniture, transport or other facilities) they are often dependent on others, which makes it more difficult to travel far distances to a hospital and to take care of themselves. Thus, seeking help for their (physical) condition consumes a lot of time and effort for people with leprosy-related disabilities, and further limits their income generation possibilities.

DISCUSSION

In this study, the QOL, participation, activity and perceived stigma of leprosy-affected people were compared with those of the general population, and the association with socio-demographic variables was examined. Significant differences were observed in the educational level, occupational status and monthly household income between the people with leprosy-related disabilities and community controls. These differences confirm findings in three past studies in Bangladesh and India, showing that people with leprosy-related disabilities have lower educational and employment opportunities compared to the general population (11, 15, 16).

Moreover, people with visible signs of leprosy in particular seem deprived of higher education and suffer from unemployment. It is not known to what extent they are unemployed due to lack of educational opportunities. Women were more severely affected than men, confirming the difference in attitude of the family and community towards a disabled man and woman as described in the "Country Profile on Disability, Kingdom of Nepal" (17). A woman with disabilities is often seen as a great burden to the family, while a man would still be encouraged to participate in activities both at home and in the community (17). However, this only holds true assuming that leprosy-related disabilities have, in this aspect, the same consequences as other disabilities.

People with leprosy-related disabilities had significantly worse total WHOQOL-BREF scores and lower physical, psychological, social and environmental subdomain scores than the general population. This indicates that leprosy-related disabilities affect all aspects of everyday life. The effect of disability found in this study is larger than that found in a similar study performed in Bangladesh, where only significant differences in the physical and psychological domain were found (4). The differences in the physical and psychological domain could be explained by the presence of visible impairments, and the fact that these are caused by leprosy (4). Despite the recognition more than 20 years ago that the psychiatric hazards of the disease are as bad as its physical manifestations, there are very few studies that explicitly focus on the psychological problems of people affected by leprosy (18). Scott (2000) and Floyd-Richard and Gurung (2000) found that grief, fear, feelings of worthlessness and rejection were the most common emotions of leprosy-affected people (19, 20). These emotions seemed to originate from the worry about financial matters, losing one's job, being stigmatised by family and community, possible divorce and loneliness. However, the study by Scott was performed in South-Africa and the psychological needs of people affected by leprosy in this study could therefore have been dissimilar to the needs of leprosy-affected people in the present study area (20).

According to the WHO (1997), the social domain of the WHOQOL-BREF reflects how content people are with their personal relationships, sex life and social support from family and friends (10). It appears from this study, that people affected by leprosy are not satisfied with their social life. This is likely to be caused by the fact that poor families are forced into an even less advantageous financial position when having to provide for the person with disability if they do not have their own income, and valuable income-generating time is spent to help this person in performing daily activities (17). The articles of Calcraft (2006) and de Stigter (2000) argued that discrimination and social stigmatization are also still highly prevalent (1, 21). This seems especially so in the case of women (22). In the past, Ulrich et al (1993) revealed that, while in leprosy-endemic areas of the world, women usually carry the major responsibility for the health of their families and household, they suffer the most from social dependency and feelings of inferiority. This is heightened by the social stigma associated with leprosy (23). In this study area, this view still seems applicable today. The negative behavior in the community was found to originate from the fear of infection and the fear of a curse from God (1, 21).

Family members and friends themselves may also be affected by social stigma, which may lead to humiliation. In turn, this can result in a deterioration of the social relationship with the leprosy- affected person. This is reflected in the fact that, not infrequently, the husband or wife files for divorce when their partner develops leprosy. According to an article on disability and poverty, women with disabilities are twice as prone to suffer divorce, separation, and violence as non-disabled women (24). If the person affected by leprosy is not married, he or she is sometimes ostracised by the family (to avoid catching leprosy). The fact that a partner or family is willing to act in this way towards a person affected by leprosy shows the degree to which leprosy is still feared in the local culture, overriding the importance of marriage and family ties (1, 21). This confirms the findings of Calcraft (2006) and de Stigter (2000), who stated that leprosy is more than a disease. Since being cut-off from one's family is generally unthinkable in this culture, this reflects the tremendous effects leprosy can have on a person and a family (1, 21).

Comparison of QOL, stigma and participation and activity scores between people with DGI and DGII revealed that for both sexes, the latter had worse total QOL scores than those with anaesthetic limbs. This difference was not found in all the QOL-subdomains. The fact that visible impairment has a large effect on the risk of stigma and on income loss due to participation and activity restrictions, agrees with the observation of Calcraft (1). With this study, the authors therefore provide evidence to support this association. In both disability groups, women showed significantly lower scores on the psychological and social domain of QOL and had higher participation restrictions, activity limitations and perceived stigma than men. An explanation for these findings could be that one of the most important ethnic groups in this study area are the Maithili, who are known for their religious devotion and traditional conservative behaviour. In the Maithili culture, the men are dominant and women are highly constrained in all aspects of life (1). The norm in this society is for a woman to remain in the house once married, and carry out housework. In this culture, a woman would only be considered successful and healthy if she were fulfilling the expected role in society and in the family (25). However, the degree to which this affects the findings of this study needs to be investigated in more detail.

Due to evidence of an interaction effect between disability grade and sex, the multiple regression analysis was performed separately for disability grade. Except for age, the findings of Tsutsumi et al. (5) were similar to those of the authors. The ability to maintain a family, satisfaction with health, vocational training, sex, activity limitations, perceived stigma and living situation (i.e. joint family, type of house) were significantly associated with QOL and participation restriction in one or both of the grading groups (4). The fact that people with leprosy related disabilities who are living in joint families have a lower QOL, could well be explained by the social stigma on the person and their families, thereby leading to social exclusion in daily family activities (eating, housework) and cultural or religious activities. Especially for women who had leprosy related disabilities and visible impairments, financial security, social dependency, educational level and stigma strongly affected QOL and social participation.

In a former study from Nepal, persons affected by leprosy with perceived stigma had delayed access to health services, resulting in an increased risk of disability and less adherence to compliance (10, 26). This adds another reason for reducing stigma, which should also be one of the priorities to achieve an increase in social participation and improve QOL (10, 27). In order to identify the characteristics of those who are most affected by stigma, and to target the problems that are faced, more detailed information and specific interventions are needed . Especially, women affected by leprosy should be an important target for interventions, because they face several disadvantages simultaneously, such as difficulties in performing traditional gender roles, participating in community life, and accessing rehabilitation services provided by male service providers.

The present study had several limitations which may have compromised the results. The design was cross-sectional and could therefore not reveal any definite cause-and-effect relationships. Furthermore, the goal of the sampling method was to include affected persons from multiple sections of Morang district, based on the relative prevalence of leprosy- affected people in each VDC. Logistic difficulties, however, led to more persons being enrolled from Biratnagar than from rural areas. The Leprosy Referral Centre in Biratnagar is the most important one in the district and most people affected by leprosy attend this hospital. This makes it representative for Morang district, but not for the whole of (East) Nepal. During the data collection the authors encountered various issues. One significant obstacle was that, due to cultural limitations, there were difficulties in obtaining the social domain scores of the WHOQOL-BREF. In some communities question 21 of the WHOQOL-BREF ('How satisfied are you with your sex life?') was not considered an acceptable question to ask. During the interview-based questionnaires efforts were made to ask the question more indirectly, so scores could still be obtained. When a score for this question was not obtained, the missing item was substituted by the mean of the other items in the domain (10). According to the WHOQOL-BREF instruction manual, this does not interfere with the validity of the questionnaire. Only when > 1 item is missing of domain 3, the domain score should not be calculated.

CONCLUSION AND RECOMMENDATIONS

It is concluded that the QOL of people with leprosy-related disabilities is significantly lower than that of the general population. Furthermore, QOL, activity limitations, participation restrictions and perceived stigma are worse among people with leprosy-related visible impairments. There is a direct relationship between a lower QOL, participation restriction, activity limitations and the presence of perceived stigma. For both disability grade groups it appears that the ability of providing food, financial support or other necessities for one's family, is a major determinant for the level of QOL. Activity limitations, participation restrictions and stigma limit this ability and therefore have an adverse effect on QOL. Regarding the participation restrictions, it seems that women suffer the most from restrictions due to gender-related cultural values and beliefs in the study area. This appears to have a negative impact on their social dependency and psychological status and is reinforced by the stigma on leprosy which is still present in the communities.

The key role of disability in quality of life and social participation reiterates the importance for leprosy programs improving early identification of new cases and referral of patients with complications. More public awareness should be created, especially in women, to improve early recognition of the disease and the problems faced by those affected. This may also help to change community attitudes resulting in a reduced social stigma. Another important strategy would be to strengthen the network of leprosy-affected people. If an association of affected people would empower their members, they could disseminate their experience and knowledge concerning leprosy in the community. With appropriate financial support to start income generating activities and/or the provision of vocational training, people affected by leprosy can improve their livelihood. As a result, their self-confidence level is likely to increase and perceived stigma may decline.

In addition, awareness should be created among VDC leaders and government officials that addressing disability issues is also part of community development. People with leprosy-related disabilities – in particular women – should be encouraged to be involved in all community development activities, according to their potential. Access to mainstream education should be facilitated for people affected by leprosy, who cannot pay school fees or did not have education for other reasons. A detailed needs assessment will need to be done to plan more specific rehabilitation interventions.

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REFERENCES

1. Calcraft J.H. ***The effects of the stigma of leprosy on the income generation of leprosy affected people in the Terai are of south east Nepal.*** Asia pacific disability rehabilitation journal. 2006; 17(2):73-89.
2. Disability MB and Child proportion- Epidemiological significance and interpretation. [website: nlep.nic.in/pdf/DisabilityMBChild%20proportion.pdf]
3. Joseph GA, Rao S. ***Impact of leprosy of the quality of life.*** Bulletin of World Health Organization, 1999, 77: 515-517. PMid:10427937 PMCid:2557686
4. Tsutsumi A, Izutsu, Islam A, Maksuda, AN, Kato H., Wakai S. ***The quality of life, mental health and perceived stigma of leprosy patients in Bangladesh,*** Social Science & Medicine 2007, 64: 2443-2453. doi:10.1016/j.socscimed.2007.02.014
5. Tsutsumi A, Izutsu T, Islam A, Jalal UA, Nakahara S, Takagi F, et al. ***Depressive status of leprosy patients in Bangladesh: association with self-perception of stigma,*** Leprosy Review 2004, 75: 57-66. PMid:15072127
6. ShuMin C, DiangChang L, Bing L, Lin Z, XiouLu Y. ***Assessment of disability,social and economic situations of people affected by leprosy in Shandong Province, People's Republic of China.*** Leprosy Review September 2003, 74(3): 215-221. PMid:14577466
7. Declaration of elimination of leprosy as a public health problem in Nepal [website: www.searo.who.int/LinkFiles/cds_press_release_leprosy_jan10.pdf]
8. Leprosy in Nepal, the Nippon Foundation [website: http://blog.canpan.info/tnf/archive/33]
9. Netherlands Leprosy Relief Nepal, Annual Progress Report 2065/2065 (2007/2008), A report contributing to the better understanding of NLR supported Leprosy control program in Nepal.
10. World Health Organization. ***WHOQOL-BREF instruction, administration, scoring and generic version of the assessment.*** Geneva: World Health Organization 1996.
11. World Health Organization. WHOQOL:Measuring quality of life. Geneva: World Health Organization 1997.
12. Bhattarai PC, Niessen L, Shrestha N, Samir KC. ***Health Related Quality of Life of adults in Nepal with respiratory symptoms using WHOQOL and EQ-5D.*** 2005.
13. Van Brakel WH, ***Measuring health-related stigma-a literature review.*** Psychol Health Med, 2006. 11(3): p. 307-34. doi:10.1080/13548500600595160.
14. Van Brakel WH, et al. ***A scale to assess activities of daily living in persons affected by leprosy.*** Lepr Rev, 1999. 70(3): p. 314 PMid:10603721
15. Van Brakel WH, A Officer ***Approaches and tools for measuring disability in low and middle-income countries.*** Lepr Rev, 2008. 79(1): p. 50-64 PMid:18540237.
16. Participation Scale User Manual version 5.2. Date of last revision: 09-07-2008.
17. Country Profile on Disability, Kingdom of Nepal, March 2002.
18. Mhasawad BC. ***Leprosy-a case for mental health care.*** Leprosy in India, 1983;55, 310- 313.

19. Scott J. ***The psychosocial needs of leprosy patients.*** Lepr Rev, 2000. 71(4): p. 486-91 PMid:11201903

20. Floyd-Richard M, S. Gurung. ***Stigma reduction through group counselling of persons affected by leprosy--a pilot study.*** Lepr Rev, 2000. 71(4): p. 499-504.PMid:11201905

21. De Stigter DH, L. de Geus, ML Heynders. ***Leprosy: between acceptance and segregation. Community behaviour towards persons affected by leprosy in eastern Nepal.*** Lepr Rev, 2000. 71(4): p. 492- 8. PMid:11201904

22 Schuller et al. ***The way women experience disabilities and especially disabilities related to Leprosy in rural areas in South Sulawesi, Indonesia.*** Asia Pacific Disability Rehabilitation Journal, 2010;Vol. 21 No.1.

23. Ulrich M, et al. ***Leprosy in women: characteristics and repercussions.*** Soc Sci Med, 1993. 37(4):p. 445-56. doi:10.1016/0277-9536(93)90280-H

24. Elwan A. ***Poverty and Disability: a survey of the literature.*** Background paper WDR, 1999.

25. Goudel C. ***A report on disability in the western region of Nepal.*** Asia Pacific Disability. Rehabilitation Journal, 2004, Vol. 15, No. 2.

26. Hyland JA. ***A socio-cultural study of leprosy in Nepal: compliance, patient illness career patterns, and health education.*** Ph.D. dissertation 1993, University of Tasmania.

27. Cross H, Choudhary R. ***STEP: An intervention to address the issues of stigma related to leprosy Southern Nepal.*** Lepr Rev 2005, 76, 316–324.PMid:16411511.

Table 1: Socio-demographic variables for people with leprosy-related disabilities (separated for disability grade DGI/DGII) and controls separated for sex (The Chi-square is calculated only for the numbers in bold since stratification results in a considerable reduction of group size).

Socio-demographic variables (number, (%))	Male			p-value	Female			p-value
	DGI n= 33	DGII n=28	Controls n=59		DGI n=21	DGII n=18	Controls n=41	
Educational level Illiterate	11 (33.3)	9 (32.1)	15 (25.4)	0.93	9 (42.9)	15 (83.3)	18 (43.9)	0.02
Literate	22 (66.7)	19 (67.9)	44 (74.6)		12 (57.1)	3 (16.7)	23 (56.1)	
Primary school	12 (36.4)	12 (42.9)	20 (33.9)		10 (47.6)	2 (11.2)	20 (48.8)	
Lower sec. school	6 (18.2)	3 (10.7)	11 (18.6)		-	1 (5.6)	1 (2.4)	
Sec. school and above	4 (12.1)	4 (14.3)	13 (20.4)		2 (9.5)	-	2 (4.9)	
Occupational status Unemployed	2 (6.1)	8 (28.6)	2 (3.4)	0.001	2 (9.6)	9 (50.0)	3 (7.3)	0.001
Unemployed/leprosy	1 (3.0)	6 (21.4)	-	-	5 (27.8)	-		
Unemployed/other causes retired	-	1 (3.6)	2 (3.4)		1 (4.8)	2 (11.1)	1 (2.4)	
	1 (3.1)	1 (3.6)	-		1 (4.8)	2 (11.1)	2 (4.9)	
Employed	31 (93.9)	20 (71.4)	57 (96.6)		19 (90.4)	9 (50.0)	38 (92.7)	
Agriculture	8 (24.2)	6 (21.4)	15 (25.4)		7 (33.3)	4 (22.2)	12 (29.3)	
Private	8 (24.2)	1 (3.6)	1 (1.7)		1 (4.8)	-	-	
Business	12 (36.4)	7 (25.0)	23 (39.0)		2 (9.5)	1 (5.5)	11 (26.8)	
Student	2 (6.1)	5 (17.9)	13 (22.0)		3 (14.3)	1 (5.6)	6 (14.6)	
Other	1 (3.0)	1 (3.6)	3 (5.1)		6 (28.6)	3 (16.7)	9 (19.5)	
Income/month (Rs.) No income	4 (13.0)	8 (28.6)	5 (8.5)	0.03	3 (14.3)	6 (33.3)	9 (19.5)	0.003
Income	29 (87.0)	20 (71.4)	54 (91.5)		18 (85.7)	12 (66.7)	32 (80.5)	

	Male DGI n= 33	DGII n=28	Controls n=59	p-value	Female DGI n=21	DGII n=18	Controls n=41	p-value
<500	1 (3.7)	4 (14.3)	2 (3.4)		1 (4.8)	7 (38.9)	3 (7.3)	
500-1000	5 (14.8)	4 (14.3)	3 (5.1)		6 (28.6)	3 (16.7)	10 (26.8)	
1000-2000	8 (24.1)	2 (7.1)	15 (25.4)		7 (33.3)	2 (11.1)	14 (34.1)	
2000-4000	10 (31.5)	4 (14.3)	17 (28.8)		4 (19.0)	-	4 (9.8)	
4000-6000	3 (11.1)	6 (21.4)	12 (20.3)		-	-	1 (2.4)	
6000-8000	-	-	2 (3.4)		-	-	-	
8000-10000	-	-	2 (3.4)		-	-	-	
>10000	1 (1.9)	-	1 (1.7)		-	-	-	

* Chi-square test

Table 2: WHOQOL-BREF, GPAS and Participation scores of people with leprosy-related disabilities and controls

	Cases (n=100) Mean (SD)	Controls (n=100) Mean (SD)	p-value
WHOQOL-BREFtotal[a]	81.9 (13.90)	91.2 (8.24)	0.001
Q1 (satisfaction with life)[a]	3.05 (0.85)	3.72 (0.51)	0.001
Q2 (satisfaction with health)[a]	2.88 (0.95)	3.64 (0.58)	0.001
Physical[a]	24.1 (4.85)	27.4 (3.54)	0.001
Psychological[a]	20.67 (4.03)	24.1 (2.45)	0.001
Social relationships[a]	10.9 (1.69)	11.4 (1.44)	0.029
Environmental[a]	26.45 (4.22)	28.3 (3.55)	0.001
GPAS score[u]	24.8 (21.1)	2.39 (3.94)	0.001
Participation score[u]	20.2 (34.4)	2.23 (4.41)	0.001

a=ANOVA for WHOQOL-BREF scores, b= Mann-Whitney U test for GPAS and Participation restriction scores.

Table 3: WHOQOL-BREF, GPAS and Participation scores for males and females affected by leprosy (separated for DGI and DGII).

	DGI		p-value		DGII		p-value		p-value
	Male (n=33) mean (SD)	Female (n=21) mean (SD)		Total (n=54) mean (SD)	Male (n=28) mean (SD)	Female (n=18) mean (SD)		Total (n=46) mean (SD)	DGI vs. DGII
WHOQOL-BREF total[a]	89.0 (11.9)	85.3 (6.56)	0.03	87.6 (10.2)	77.6 (12.24)	71.5 (12.9)	0.92	75.24 (12.7)	0.14
Q1 (satisfaction with life)[a]	3.45 (0.75)	3.33 (0.58)	0.10	3.41 (0.69)	2.79 (0.83)	2.39 (0.78)	0.76	2.63 (0.83)	0.33
Q2 (satisfaction with health)[a]	3.21 (0.98)	3.29 (0.64)	0.14	3.24 (0.80)	2.54 (1.00)	2.33 (0.84)	0.29	2.46 (0.94)	0.11
Physical[a]	26.3 (3.73)	25.8 (3.19)	0.36	26.1 (3.51)	22.7 (5.36)	20.6 (4.89)	0.76	21.9 (5.23)	0.01
Psychological[a]	22.2 (3.55)	21.9 (2.49)	0.05	22.1 (3.15)	19.8 (4.28)	17.8 (4.31)	0.96	19.0 (4.36)	0.02
Social relationships[a]	11.6 (1.94)	11.1 (1.34)	0.04	11.4 (1.73)	10.3 (1.68)	10.3 (1.09)	0.06	10.3 (1.46)	0.17
Environmental[a]	29.1 (4.72)	26.6 (2.50)	0.13	28.1 (3.99)	24.8 (3.72)	24.1 (3.68)	0.57	24.5 (3.68)	0.82
GPAS score[u]	11.1 (21.8)	6.86 (8.27)	0.86	9.43 (17.8)	42.6 (43.7)	43.0 (35.5)	0.60	42.8 (40.3)	<0.001
Participation score[u]	10.6 (13.3)	12.9 (11.6)	0.32	11.5 (12.6)	23.4 (21.8)	41.5 (24.7)	0.03	30.5 (24.4)	<0.001
Jacoby score[u]	0.03 (0.17)	0.43 (1.08)	0.11	0.19 (0.70)	1.04 (1.23)	1.44 (1.38)	0.32	1.20 (1.29)	<0.001

a=ANOVA for the WHOQOL-BREF scores, b= Mann-Whitney U test for the GPAS, Participation restriction and Jacoby scores

Table 4: Linear regression models of WHOQOL-BREF total scores separate for people with DGI and DGII.

	Univariate analysis			Multivariate analysis		
Variable	Coefficient	SE	*p*	Coefficient	SE	p
People with disability grade 1*						
Ability to maintain family	3.39	1.27	0.01	3.07	0.75	<0.001
Satisfaction with health	8.75	1.30	<0.001	7.48	1.12	<0.001
Activity score	-0.27	0.070	<0.001	-0.11	0.050	0.042
Training	-10.8	4.22	0.014	-11.3	2.49	<0.001
Caste	-0.74	0.85	0.39			
Educational level	2.54	1.04	0.020			
Type of home	-5.87	1.67	0.001			
People with disability grade 2**						
Ability to maintain family	4.62	1.58	0.005	3.30	1.19	0.008
Satisfaction with health	7.92	1.67	<0.001	4.75	1.61	0.005
Participation score	-0.33	0.061	<0.001	-0.20	0.063	0.002
Study opportunity	-7.30	6.33	0.051			
Occupation	-1.49	0.67	0.032			
On medication	-19.1	8.85	0.037			
Stigma score	-3.23	1.40	0.026			
Activity score	-0.18	0.040	<0.001			

* R^2 this model: 0.71; ** R^2 this model: 0.57

Table 5: Quantile regression models of Participation scores separate for people with DGI and DGII

	Univariate analysis			Multivariate analysis		
Variable	Coefficient	SE	*p*	Coefficient	SE	*p*
People with disability grade 1*						
Sex	-5.0	4.45	0.266	-7.02	2.55	0.008
Activity score	0.33	0.12	0.007	0.40	0.068	<0.001
Satisfaction with health	-6.33	2.89	0.033			
Marital status	-8.0	4.58	0.086			
People with disability grade 2**						
Sex	-26	7.04	0.001	-11.5	4.13	0.008
Parent situation	-14	15.8	0.38	-8.8	4.0	0.033
Stigma score	17	2.0	<0.001	11.2	1.59	<0.001
Activity score	0.40	0.12	0.002	0.17	0.050	0.001
Satisfaction with health	-6.33	2.89	0.033			
Caste	-5.0	2.67	0.068			
Study opportunity	26	7.85	0.002			
Occupation	6.13	1.74	0.001			
Income per month	-4.29	1.87	0.026			

* R^2 this model: 0.20; ** R^2 this model: 0.53