Assessment of needs and quality care issues of women with leprosy

ANAMMA SUCCHANDA JOHN*, PAMIDIPANI SAMUEL SUNDAR RAO** & SONALI DAS*
*TLM Premananda Memorial Leprosy Hospital, Kolkata, West Bengal, India
**The Leprosy Mission Trust, New Delhi, India

Accepted for publication 27 November 2009

Summary

Objectives: Leprosy causes not just physical but psychosocial and economic problems which are further magnified in women due to gender disadvantages especially in developing countries. In order to determine the needs and quality care issues of women leprosy patients attending a hospital/health care facility, a research project was done.

Design: All women leprosy patients attending a Leprosy Referral Hospital in Kolkata, India during 2006 were interviewed in depth and clinically assessed, using a standardised proforma.

Findings: Of 104 women studied, half below 40 years of age and 70% above 40 years, had visible disability, and some had diabetes, low back pain etc. Nearly 60% preferred to hide their disease but even so, some had social problems. Most women delayed going to hospital, until their husband/guardian felt it was necessary. They had to complete their household chores before setting out for the hospital, and after their return. A considerable amount of time was spent waiting at various service points which conflicted with their domestic work, and lowered their social worth if they were away too long. This de-motivated them from visiting hospitals, even for follow up visits. Medical advice given – such as avoiding prolonged walking and standing, working with hot utensils etc., was not practical.

Conclusion: Hospitals can do much to address the needs of women leprosy patients and provide quality services. National programmes should give a higher priority to offering culturally acceptable health education to promote early reporting.
Introduction

Leprosy, a stigmatised disease caused by *M. leprae*, which manifests a variety of signs and symptoms may be ignored in the early stages until visible disabilities occur. Leprosy results in not only physical problems, but also mental, social and economic consequences. In women, these problems are magnified by the gender disadvantage that prevails in many countries. Women are not able to access medical care as easily or as soon as men due to cultural, socioeconomic and psychological constraints. Hospital statistics show fewer women than men, and this may not necessarily be due to lower occurrence or severity of a disease. Several articles have referred to 'double jeopardy’ in relation to women with leprosy in developing countries.

Leprosy-affected women are less likely to report early, and not until the disease prevents them from carrying out their domestic responsibilities. Health services are responsible for educating and motivating patients to report promptly, adhere to treatment schedules and to provide holistic health care and quality services. They need to respond to the felt needs of women to ensure patient satisfaction and better co-operation between patients and health professionals.

A research project was carried out on women patients attending a leprosy referral hospital in Kolkata, West Bengal, to determine the extent to which women patients were satisfied with leprosy treatment and supporting services, to assess their further needs, and to evaluate their knowledge of leprosy.

Materials and Methods

All women leprosy patients attending The Leprosy Mission Premananda Memorial Hospital in Kolkata during 2006 were interviewed by a trained female investigator using a specially prepared interview check list. This included the socio-demographic and leprosy profile of the women, their knowledge and attitudes to leprosy, their needs and expectations from the hospital and their satisfaction of the services provided. The women were further examined and interviewed by the first author, and clinical details were collected to supplement the routine information in the hospital chart. The interviews normally took an hour to complete, and often at more than one session. The data were entered onto a computer and analysed using SPSS software.

Results

A total of 104 women were studied, 47 (45%) from within the Kolkata district and 57 (55%) from outside the district. Forty-six (44%) were below 40 years of age; 17 (16.3%) were unmarried, 55 (52.9%) were currently married, 19 (18.3%) were widowed and the remaining 13 (12.5%) were separated or divorced. Among those below 40 years, nearly 40% were illiterate, 34% had primary schooling and the remaining 26% had studied up to high school or more. Of those above 40 years, nearly 40% were illiterate, another 40% had primary schooling and the remaining 20% only had high schooling. Nearly 63% belonged to poor socio-economic groups, 30% were middle class and only 7% were from higher socio-economic groups. Almost all came by public transport, train or bus and rickshaw; 44% came alone, 30% were...
brought by their father or husband, and the remaining 26% had some relative or friend accompanying them; 93% of the women had leprosy-related problems. The leprosy profile by age is shown in Table 1.

Nearly half of women below 40 years of age, and 70% above 40 years had visible disabilities; 4% below 40 years, and 27.6% above 40 years had an eye complication. A few patients had other non-leprosy problems such as diabetes and low back pain. For nearly 90% of patients, this was a repeat visit for follow-up or further treatment, mostly for recurrence of reactions, ulcers or other complications. The knowledge on leprosy is presented in Table 2.

The majority stated that leprosy was treatable with tablets, and that the treatment was free. Almost all patients expected to receive counselling, health education and self-care skills. Nearly 60% of patients were referred, and the remaining came on their own or on the advice of a friend. Around 60% preferred to hide their disease (even though they could not hide the deformity they hid the diagnosis), and a few stated that even so, they had social participation restrictions.

In general, the women had to delay going to hospital, till their husband or guardian felt it was necessary (see case reports). Most women had to complete their household chores before setting out for the hospital. They also had several domestic jobs waiting to be completed when they returned. Over a third of women spent more than 3–4 hours travelling each way. The more time they spent in the hospital, the longer was their absence from home, conflicting

Table 1. Profile of patients according to leprosy characteristics

| Characteristic                  | Below 40 (46) | 40 & over (58) | Total (104) |
|--------------------------------|---------------|----------------|-------------|
| Reason for hospital visit:     |               |                |             |
| Leprosy related ulcers         | 9 (19.6%)     | 29 (50.0%)     | 38 (36.5%)  |
| Reactions/other complications  | 24 (52.2%)    | 18 (31.0%)     | 42 (40.4%)  |
| MDT                            | 8 (17.4%)     | 6 (10.3%)      | 14 (13.5%)  |
| Footwear & others              | 5 (10.9%)     | 5 (8.6%)       | 10 (9.6%)   |
| WHO Disability grade:          |               |                |             |
| 0                              | 22 (47.8%)    | 10 (17.2%)     | 32 (30.8%)  |
| I                              | 3 (6.5%)      | 8 (13.8%)      | 11 (10.6%)  |
| II                             | 21 (45.7%)    | 40 (68.9%)     | 61 (58.6%)  |

Table 2. Knowledge and Attitudes of Women by Age

| Knowledge/Attitude          | Age (Years) |
|-----------------------------|-------------|
|                             | Below 40    | 40 & over    |
| Early Signs:                |             |             |
| Patch and Anaesthesia       | 22 (47.8%)  | 31 (53.4%)  |
| Cause:                      |             |             |
| Bacterial infection         | 35 (76.1%)  | 42 (72.4%)  |
| Leprosy is curable          | 40 (87.0%)  | 47 (81.0%)  |
| Leprosy treatment is free   | 43 (93.5%)  | 55 (94.8%)  |
| Deformity can be prevented  | 37 (80.4%)  | 45 (77.6%)  |
with their domestic work, and their social worth in terms of their roles and responsibilities was affected if they are away too long. This de-motivates women from coming to the hospital very often unless the problem is severe.

Sixty percent were satisfied with the outcome of their treatment mentally and physically, though problems such as ulcers and reactions continued to recur. They felt that the hospital was providing the best care, but that the disease cannot be cured completely. They found repeated visits to the hospital rather difficult due to the cost, time away from domestic responsibilities, and lack of cooperation from family members.

During the course of interviews with the first author, a majority of women revealed that they had no knowledge of leprosy prior to coming to the leprosy centre. Had they known that deformities could be prevented by early treatment they would have tried to come sooner. All of them expected their physical problems to be solved conclusively and were disappointed with the recurrence of ulcers, neuritic pain and reactions. It was difficult for them to follow the medical advice given such as avoiding prolonged walking and standing, and working with hot utensils as they had to care for their families and also augment their family income. Social and economic problems faced by the women due to leprosy had been addressed in some cases by providing educational grants for children, soft loans for small business ventures, vocational training, and in a few cases reuniting them with their families. The patients appreciated the time given to them by the doctor during the interview. It appeared that just listening to their problems added to their sense of wellbeing and satisfaction even if material benefits were not always possible.

Two illustrative case reports are presented:

**CASE 1: ANSU (NAME CHANGED)**

Ansu Bibi was a happily married wife and mother when she developed pale patches on her arms and legs. Her husband felt that the symptoms were not severe enough to warrant the expense and inconvenience of medical care, so she did not take any treatment for 4 years and ignored the slowly increasing patches until she developed a reaction. This made her husband take her for treatment, but the reactions continued and ulnar paralysis developed along with ulcers on her feet. Her husband then abandoned her and she somehow managed to return to her parents in another city.

It was quite a problem for her parents to look after her due to financial constraints, and she was withdrawing more and more from society and not even speaking. She was brought to the leprosy hospital on the advice of another patient. Her physical problems have gradually improved and she has been free of ulcers and reactions for the last 2 years, but only after 12 admissions in 3 years and many visits to the clinic. She has not seen her children for 8 years. She was mentally, socially and economically in a very bad way. The leprosy hospital helped her by providing her with low cost housing, a monthly pension and regular counselling. She is gradually recovering from the mental and physical trauma and may soon be fit to earn her livelihood through some small business. Ansu feels that if she had been a man she would have been taken for treatment much earlier and would not have been abandoned by her family.

**CASE 2: ROSY (NAME CHANGED)**

Rosy was a playful village girl of 12 when she developed patches on her left arm. No one paid much attention as her mother was very sick and died soon after. Her Father remarried and was
too busy to take note of Rosy’s problems. Soon Rosy developed bilateral claw hand and a foot drop. She was brought to the leprosy hospital and MDT was started along with physiotherapy as contractures had already formed. When she went home she started developing ulcers on her hands as her stepmother expected her to help with the cooking. When the ulcers recurred after treatment, her stepmother refused to have her in the house any more. She was left in the hospital for months until her brother took her to live with him and his family. Over the next 8 years Rosy had reconstructive surgery for both her hands and foot. She was sent to a vocational training centre where she learnt tailoring. When she had finished the course, a machine was provided for her and she set up a small business, stitching clothes for people in her village. She gradually became a confident young woman. Her brother arranged a marriage for her and she is now the proud mother of a beautiful girl, living with dignity and empowered to improve her life.

Discussion

This study is based on women leprosy patients attending a popular referral clinic and may not reflect the overall problems faced by such women. However, the lessons seem to be universal in the Indian context based on a review of the literature.

Quality care implies effective, appropriate, holistic and prompt treatment at affordable rates. This assumes acceptable care that addresses both physical and psychosocial problems. In most hospitals and health care settings, inevitably, there is a greater emphasis on the medicalisation of the problems and most health professionals either have no training or no time to counsel on the cultural and psycho-social needs of the leprosy patients. Women come to hospital at great expense of time and cost because of recurring physical problems such as plantar ulcers, reactions or other medical consequences of leprosy. Unfortunately, some of these problems still defy current technical knowledge in prevention or treatment and more research is needed in solving these clinical problems.

These female patients face social restrictions as well as perceived and enacted stigma. Much has been written on the different manifestations of leprosy stigma as it affects women in developing countries. Although stigma affects all leprosy patients, women suffer more adversely. Health services have often left women and their family to cope with their distress through concealment, visiting leprosy care centres far from their homes, defaulting or seeking help through alternate medical systems. Caution must be exercised to avoid iatrogenic stigmatisation through poor patient-health professional interactions. In the case of women, because of their lack of autonomy or financial constraints, there is a greater need to offer more tangible assistance to promote their early reporting, prompt and regular treatment without unduly disturbing their domestic roles and responsibilities. Family-based and peer-group counselling could help in boosting their confidence and clearing misconceptions regarding leprosy, its complications and management and facilitating domiciliary care, whether by individuals or family members.

Given the fact that nearly 60% of women have delayed seeking hospital care, and a majority have concealed the disease, there is a great need for health service personnel to be sensitive to the need of female patients. Gender sensitivity in terms of more female staff and trained women volunteers would be helpful. Operationally, in a resource-poor situation, most hospitals may be unable to offer quality care due to lack of enough trained staff, especially women, or the inability of professional staff to give adequate time to each patient to listen to
their peculiar problems and counsel them, thereby disappointing the patients and falling short of their expectations.\textsuperscript{30,31} National programmes and leprosy NGOs need to give priority to delivering culturally acceptable health education to promote early reporting.\textsuperscript{28}

An important aspect of quality care is the provision of acceptable standards of privacy for women during examination and history taking, in providing basic amenities like separate toilets, and for special services such as prosthesis and orthotics. Patients have to spend a considerable time waiting at every station in a hospital such as at registration, body-charting, physiotherapy, and at the laboratory, and there are long delays before patients get to see a doctor. These delays adversely affect most women who are expected to return quickly to their homes.\textsuperscript{32} Special attention to women patients is needed so that time spent at clinics can be significantly reduced.

Much can be done without increased expenditure, to provide a better quality service to women leprosy patients and to address their needs more effectively. Reduction of waiting times, priority queues, adequate privacy and trained women professionals are just a few examples. Counselling should be an integral part of holistic care to help patients tackle their needs in a positive manner. Development of culture-specific health education material is a priority.\textsuperscript{27} Efforts should be made to promote early detection and treatment, especially under the present integrated set-up, with an increased focus on women.\textsuperscript{33}

Acknowledgements

We are grateful to the Director, The Leprosy Mission Trust India and to the Superintendent of the Premananda Memorial Leprosy Hospital for support and encouragement for this study. We also thank all the women patients and their families for their participation.

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