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Original Article

Determinants of rural women's participation in India's National Leprosy Eradication Programme

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A multistage representative random sample of women and men from each of the 3 states of Bihar, Uttar Pradesh and West Bengal, from the rural blocks where the Leprosy Mission Hospitals were located were selected during 2010 to identify relevant factors that are preventing active participation of women and suggest corrective steps. Adult men and women were interviewed in depth, using a detailed checklist by the first author. A total of 1239 respondents 634 women and 605 men, were interviewed. Only 44 women (7%) claimed that they had earlier participated in leprosy work, about 92% of the women felt that they had the potential to take part in leprosy work, and 70% showed willingness to participate. Factors that would encourage and facilitate more women to participate in leprosy work, included financial support (32.8%), convincing the family to grant permission(88%), and delegating them to work in proximity to their residences (15%). Some women respondents (11.0%) felt that they would provide their services voluntarily for social good. Women suggested that work should be delegated as per their capabilities and skills, and they should be given proper orientation, training and guidance. Hardly 5% of ASHA's in the clusters examined participated in leprosy related work, which needs stringent steps to re-orient and encourage them to undertake leprosy related work. It is concluded that rural Indian women are keen to play an important role in the national leprosy eradication program, with minimal support from the government and nongovernmental agencies in a truly community-based approach. This will benefit vast numbers of leprosy affected women as well as others.

Key words: Leprosy, Cultural attitudes, Stigma

Introduction

Women's participation in a country's development process is not only an issue of human rights and social justice, but critical in solving the pressing needs of society (Mokate 2004). Although half the population in a developing country are women; yet, their role in the implementation of national programmes or framing rational policies is essentially nonexistent or minimal (Siddiqui and Hussain 2009). Traditional, cultural and religious attitudes of both men and women are identified as key constraints in women's participation, particularly in the rural areas (Kongolo and Bamgose 2002, Deji 2007)

In the field of health, women are actively engaged in maternal and child health programmes but seems to have little part to play in the control

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of major public health problems such as Tuberculosis, Malaria and Leprosy, possibly due to a variety of reasons. Hardly any research has been published on these issues, especially in leprosy, where patients, both men and women, continue to suffer many medical and psychosocial problems, due to ignorance, stigma or financial/ logistical factors. That there are special needs of women has been reported (John et al 2010, Le Grand 1997) and women face double jeopardy (Morrison 2000, Viassoff et al 1996). However efficient, male health professionals are at a great disadvantage in caring or even assessing the extent of the problem of women affected by leprosy. A study in Maharashtra reported that midwives detected more leprosy among women than the leprosy paramedical (male) workers (Rao et al 1996). It is gratifying to note that integration of leprosy care within the general health system has brought in more women professionals, and the recent introduction of ASHA worker under the national rural health system has been a great boon (Park 2009). However, there seems to be a great need for women in the community to take an active role in ushering leprosy eradication through changing attitudes and behaviour as well as to enhance existing knowledge (Barkataki et al 2006). The experiences of DANLEP in India a decade ago has amply demonstrated that women's participation in Madhya Pradesh and Chhattisgarh in developing a strong community network using women's groups have made an impact on the leprosy work in the state (Sundaram and Narayanan 2003, Varkevisser et al 2009). However, similar work has not been replicated and the vast areas in India still need the critical role women can play in the health and development process, especially in a sociomedical disease such as leprosy. In order to identify relevant factors that are preventing active participation of women and take corrective steps for their involvement, a research project was done in 3 states of India during 2010 and to identify methods to facilitate such participation.

Materials and Methods

The methodology for the study consisted of selecting a multistage representative random sample of women and men from each of the 3 states chosen, viz, Bihar, Uttar Pradesh and West Bengal. One district from each state was randomly selected, Faizabad from U.P., Muzaffarpur from Bihar and Purulia from West Bengal. One rural block from each selected district, where one of the Leprosy Mission Hospital was located, was then selected at second stage: viz., Masodha from UP, Kurhani from Bihar and Purulia-I from West Bengal. A listing of all the villages in each chosen block was done, from which a stratified random sample of 5 villages was selected as the third stage to provide adequate representation of the Scheduled caste population, Muslims, villages proximate to a PHC and villages located away from the main Highway. Finally, from the chosen villages, a random sample of households were selected as the fourth stage. An adult male & an adult female from each household wherever available were interviewed using the following checklist:

Female Respondents

1 Have you in any way participated in any leprosy related work? (Such as rally, survey etc conducted by leprosy department or NGOs etc.)

2. Are you anyway connected with leprosy work? (Referred a patient to PHC)

3. Do you think you can help?

4. What difficulties/obstacles you might face?

5(i) What support you might require? (Permission from the family or community)

5(ii) What support you may require? (in the form of capacity building / IEC material / training aids)

Male Respondents

1. Do you think women should participate actively in leprosy work?
2. Do you think they can help?
3. What difficulties/obstacles women might face?

4(i) What support they may require? (Permission from the family or community)

4.(ii) What support they may require? (in the form of capacity building/IEC material/ training aids).

The interview of females was aimed to collect reliable data on whether they participated in any leprosy related work earlier, whether women should participate, their willingness to participate in future, barriers and obstacles in more active participation of women in leprosy control and identify methods to facilitate active participation.

The interview of males was aimed at whether women should participate and help in leprosy control work, the difficulties/obstacles women might face and the support required for their active participation. Specific interview check-lists were then devised to collect this information The investigators, both males and females, mostly MSW students, were locally hired, oriented to leprosy work and trained in data collection using the interview checklist. The research investigator personally visited the home, introduced herself and explained the project along with the trained investigators locally hired to collect the necessary data. The data was then coded, entered on computers and analysed using SPSS statistical software.

Results

A total of 1239 respondents have been interviewed, 634 women and 605 men. Table 1 shows the distribution of males and females in the three states from each of the village criteria mentioned earlier.

As seen from the above table, roughly half the respondents were women in each state.

About 32% males and 42% females were between 26-35 years of age; 20% are above 45 years of age. Approximately a third of males and half the females were illiterate; 20% among males and 12% among females had studied upto high school and the rest 27% males and 12% females studied beyond high school. Cultivators & Daily wage workers together constitute 50% of the samples among males. Around 19% were service class and 16% are self employed. Among females 80% constitute housewives and daily wage labourers. Around 9% are NRHM functionaries. More than 80% among males and 90% among females were married. Approximately 75-85% males and females are Hindus and rest are Muslim.

The findings related to how many women had ever participated in leprosy work are shown in Table 2.

Table 1 : Sample Studied By State, Gender and Village Criteria

Village selection criteria	UP Faizabad		West Bengal Purulia		Bihar Muzaffarpur		Total		All
	M	F	M	F	M	F	M	F	
PHC situated	35	40	40	57	57	69	130	166	296
Interior	18	23	23	40	71	45	135	108	243
Minority caste	21	32	32	42	59	44	131	118	249
Forward caste	38	45	45	41	13	23	103	109	212
Backward caste	39	24	24	22	43	87	106	133	239
Total	151	164	164	202	243	268	605	634	1239

Table 2 : Participation of Women by States

Participation of Women	UP	West Bengal	Bihar	Total
Never participated in leprosy work	157 (95.7)	183 (90.6)	250 (93.3)	590 (93.1)
Participated in case detection & leprosy survey(as per NRHM guidelines)	6(3.7)	13(6.4)	16(6.0)	35(5.5)
Escorted the patients to hospital	1(0.6)	6(3.0)	2(0.7)	9(1.4)
Total	164(100.0)	202(100.0)	268(100.0)	634(100.0)

Table 3 : Response of Women to participate and their willingness

Responses of Women	UP	West Bengal	Bihar	Total
Feel women have potential to take part in leprosy work	157(95.7)	183(90.6)	250(93.3)	590(93.1)
Women willing to participate	98(64.9)	131(70.4)	190(77.5)	419(71.9)
Total	164(100.0)	202(100.0)	268(100.0)	634(100.0)

Only 44 women (7%) claimed that they had earlier participated in leprosy work, out of which 5.5% claimed that they were involved in case detection and leprosy survey as per National Rural Health Mission (NRHM) guidelines. These women were mostly NHRM functionaries i.e. ANM, ASHA, Anganwadi worker (ICDS)or provided assistance to the women associated with NRHM program. About 1.4% women indicated that they at times accompanied them to the nearest Primary Health Centre (PHC). These few women with good rapport and their social standing were the sources of the community dwellers to approach for any kind of assistance they needed. Thus, only 3-6% of the ASHA workers in the NRHM had taken an active interest in leprosy, requiring proper reorientation and perhaps more training to motivate them.

Significantly larger number of younger women, illiterate and housewives and those in interior villages or backward castes had ever participated in leprosy work. However, about 92% of the women felt that they had the potential to take part in leprosy work. However, only 70% showed willingness to participate, as given in Table 3.

A smaller proportion, but still large have expressed their willingness to participate in antileprosy programmes. The responses of the men were very similar.

Both women and men mentioned some factors that would encourage and facilitate more women to participate in leprosy work, which included financial support (32.8%), convincing the family to grant permission (88%), and delegating them to work in proximity to their residences (15.0%). Some women respondents (11.0%) felt that they would provide their services voluntarily for social good.

Women also suggested that work should be delegated as per their capabilities and skills, and they should be given proper orientation, training and guidance.

Discussion

Knowledge and attitudes are the building blocks of behavioural change, particularly in the care seeking habits (Mukherji et al 2005). Given the insidious and often painless symptoms of leprosy,

motivating the affected persons to voluntarily report early must be given top priority in India's leprosy eradication programme (Nicholls et al 2006). The critical role women in the community can play in this process cannot be underestimated (Sinha et al 2002). The findings from this research reveal that women are keen to participate in leprosy field work, provided some minimal requirements for their security are met. This is not unreasonable, given the vulnerability of women to undertake field work, when there could be a hostile and criminal environment. These women who volunteer to help are not like the paid women workers such as the ANM, Anganwadi workers or even the ASHA worker, who have maintained their professional work, with the support from the family (Park 2009). Given the great efforts to eradicate leprosy by the NLEP, there must be a massive training program for the ASHA workers and suitable incentives for their participation in various aspects of leprosy work.

Strong traditions, the low status of women, their limited mobility, illiteracy are the realities in rural India and other developing nations, which must be justly understood and taken care of to promote full cooperation and participation of women volunteers in leprosy work (Rao et al 1999). In an era of public-private partnership, the people must be integrated for more effectiveness and greater efficiency (Rao 2010).

Participatory community approaches have always had more impact because of the counter-expertise of the people as opposed to the professionals knowledge (Fernandes and Tondan 1996). With the community involvement at all stages of a programme, from planning to evaluation, it is possible to develop and extend the range of proven interventions to address not only the problem of women, but all leprosy affected persons (Khan and Ara 2006, Behdjat et al 2009). The vertical leprosy program of the Indian government had depended almost exclusively on male workers, and the time has come to widen the base of our interventions to include women, regardless of their educational or occupational status, age or caste, as strongly voiced in this research by the various respondents, both men and women.

Half the population are women, and it is to their benefit that women be employed in leprosy work, in diagnosis, follow up of treatment and management of complications, especially among women and children.

For effective field work and support in leprosy work, women need not necessarily go into the field, but could operate from their own homes, as done in many other remunerative occupations and trades. They could function as single individuals or work on groups. They could be engaged by government or nongovernmental agencies (Hardee et al 1999). The benefits of employing women for leprosy work will be far reaching and usher the eradication of leprosy faster (WHO 2009). While the research tried to cover a variety of caste and community groups of women, further studies may be useful in other parts of India to interview other caste groups and ascertain their willingness to work in leprosy related activities to help accelerate eradication and better awareness of the public not to delay reporting and avail of the free MDT at any integrated health centre.

Conclusion

Rural women are keen to play an important role in the national leprosy eradication program, with minimal support from the government and nongovernmental agencies in truly community-based approaches. This will benefit vast numbers of leprosy affected women as well as others.

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