

Identifying the Barriers to Early Case Detection for Women Affected by Leprosy – *A Review of the Literature*

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Abstract

Objective The objective of this review was to recognise the current literature surrounding the experience of women affected by leprosy, in order to gain a wider understanding of the female-specific barriers to early case detection.

Methodology The review used a systematic search process in order to identify gender-related publications using robust research, useful for gleaning a cross-cultural perception of issues women may confront on the prospect of a diagnosis of leprosy.

Results Identifying 15 publications from just five countries, the review found there to be four overarching areas which may be considered barriers more often faced by women: societal stigma, women's dependence and low status, self-stigmatising attitudes, and the gender insensitivity of leprosy services.

Recommendations The review recommends that more attention must be paid to the individual needs of women in order to encourage early self-reporting of leprosy symptoms. This could be achieved through increased involvement in female empowerment interventions; ensuring staff are well aware of gender issues within the reporting process; increased sensitivity within family and patient counselling and a greater involvement in information, education and communication initiatives working within targeted communities.

Introduction, background and objective

The aim of this paper is gain a wider understanding of potential reasons for late diagnosis of women affected by leprosy, giving possible explanations for the gender disparity observed in case detection globally. The review focusses on articles which detail how women experience leprosy and stigma as central themes.

Studies pertaining from across the globe continue to show the disparity between the number of male and female patients being diagnosed with leprosy;¹⁻³ as well as suggesting that woman are more likely to present later for treatment.^{4,5} Nerve damage is a well-known outcome of delaying diagnosis and treatment of leprosy, with the potential to cause long lasting physical disabilities.⁶ Yet the problem with leprosy is that it is as much a social issue as a medical one. The effects of leprosy can be felt not only in physical sensations, or lack thereof, but also socially, economically and emotionally.⁵ The stigma which surrounds leprosy and those who are affected by it in countries the world over, can have such a detrimental impact on many aspects of life, that many people feel admitting or acknowledging for themselves their condition to be too risky a decision. Leaving these early warning signs untreated can have long-term debilitating effects, therefore ensuring early case detection and treatment by removing stigma is vital in order to see complete elimination of the disease worldwide.

Women can be triply disadvantaged with regard to health concerns, due to their gender, potential disabilities, and the societal stigma which arises from them.⁷ It is commonly understood that gender inequality plays a key role in the development of nations, both economically and socially. When women are not given equal opportunities in private or public life, one half of a community is silenced, unrepresented and unable to share their point of view with the whole. When one gender is traditionally dominant over the other, dependence within this relationship can be created. If this dependant relationship breaks down, it can leave one party in a much more trying position than the other, particularly when resources are scarce. This review aims to make apparent the current research surrounding the experience of women affected by leprosy in typically patriarchal societies where they have historically and continue to hold lower social status. It will explore the role this imbalance plays within efforts for early case detection of leprosy among women.

The latest World Health Organisation⁸ data on leprosy clearly highlights a global trend between the numbers of new male to female cases. The below table displays these results among countries in Africa, the Americas and South-East Asia. Countries marked with an asterisk are those included within the data reviewed in this paper; the other countries are included as a comparison of the regions included within the review.

Table 1: WHO 2014 Global Leprosy Update

Region and Country	No. of new cases detected (2014)	No. of females among new cases	% of females among new cases
Africa			
Nigeria*	2 983	1 277	43%
United Republic of Tanzania	1 947	701	36%
Democratic Republic of Congo	3 272	1 514	46%
Americas			
Brazil*	31 064	14 109	45%
Colombia	423	154	36%
Venezuela	513	174	34%
South-East Asia			
India*	125 785	46 379	37%
Indonesia*	17 025	6 370	37%
Nepal*	3 046	1 115	37%

The data demonstrates that every country listed above, and almost every country in the WHO global report, women are less represented in new cases detected. Other literature, such as Peters & Eshiet's⁹ study of over 2,000 adults affected by leprosy in Nigeria, confirm that women have a much longer duration of illness between first symptoms and presentation for diagnosis, at almost twice as long. There is no medical evidence to suggest, within the authors knowledge, that leprosy is more inclined to infect men over women. It may be possible, however, that men are more likely to come into contact with a greater social network outside of the household and therefore, have an increased risk in contracting leprosy. Nevertheless, a higher risk of contracting leprosy has been demonstrated through frequent and intense contact groups¹⁰, such as within the household. There are an increasingly large number of studies which attribute this disparity with social gender inequalities. The key findings of the majority of these studies will be disused in this review, with the expectation that gaining an understanding of why women are less inclined to present symptoms of leprosy might aid in the

development of better interventions to more fully meet their needs and alleviate the barriers to treatment.

Methodology of the literature search

A systematic process was used for this literature review, which comprised a number of stages, used across a number of databases. Beginning with the question “*What are the reasons for gender disparity in reporting figures among people affected by leprosy?*” in mind, the following stages were addressed:

- Identifying potential studies via accessible and relevant databases
- Using the inclusion and exclusion criteria to sift through potential studies and narrow down to only those meeting all requirements
- Examining remaining studies in depth to assess quality and extract relevant evidence to support the review question
- Developing a structure for analysis of relevant data and identifying key themes
- Writing up findings within the decided structure for the review

Elements of the literature search

Electronic databases used for the search:

- INFOLEP
- MEDLINE
- ScienceDirect
- Scopus
- JSTOR
- PhychINFO
- CINAHL Complete
- Social Sciences Citation Index

Exclusion Criteria:

- Excluded if they did not meet all of the inclusion criteria
- Any articles published before 1996 in order to retain a 20 year relevancy in case of changing gender roles or attitudes
- Any research which did not directly focus on the way women experience leprosy

Inclusion Criteria:

- Primary research
- Publication years 1996-2016 inclusive
- In-depth qualitative studies to involve 10 or more participants
- Quantitative studies to involve over 100 participants.
- Studies must examine the experience of women affected by leprosy, either at a small scale and in-depth, or on a large scale, looking at trends appearing from the data as to why certain circumstances for women were contributing to their lack of participation

Key words used to select publications:

- Leprosy
- Gender relations
- Female, women, woman
- Experience
- Delay in treatment
- Health seeking behaviour
- Stigma, social shame, self-stigma, prejudice, discrimination
- Low social status, economic dependency
- Health workers
- Belief, tradition(al)
- Early case detection

Results of the Literature Search

The literature search identified 15 publications^{2-5,11-21} describing the experiences of women affected by leprosy, recognising potential female-specific reasons attributed for the late diagnosis of leprosy. Publications were only selected for the review if they dealt directly with women affected by leprosy and had a robust analysis of original primary data. The only countries subject to research within this review are India, Nepal, Nigeria, Indonesia and Brazil. Evidently, these countries each have widely different cultures and traditions concerning the status and roles of women, and it is therefore enormously difficult to generalise the experience of women affected by leprosy between them. However, the identified themes are so broad, and these extensive findings so similar between countries that *some* overviews can be drawn from the literature. This concern was held in mind throughout the analysis of the literature, yet was impossible to avoid due to the limited number of articles fitting the criteria of the review. The findings within these articles are grouped into four areas for exploration which may be attributed to the late diagnosis of women, as suggested throughout the literature:

- Experience of Societal Stigma (twelve primary sources)
- Low Status and Economic Dependence (fourteen primary sources)
- Inner-Wellbeing: Self-Stigmatizing Attitudes (eight primary sources)
- Gender Insensitivity of Leprosy Services (eleven primary sources)

Experience of Societal Stigma

The review identified twelve articles which discuss the stigmatising attitudes women affected by leprosy experience from others in their community, including those within their family. Having been known to humanity for millennia, the long history of leprosy has enabled the incubation of traditional beliefs and stigmatising attitudes surrounding the disease to become embedded within societies around the world, due to the fear of incurability and the visible disability which results from nerve damage. In many parts of the globe a diagnosis of leprosy brings with it the fear of being ostracised by one's community, often due to a severe lack of medical awareness; particularly in remote areas where medical resources are scarce. While it is true that this societal stigma can affect both men and women, there are particular aspects of the cultural expectations of women in the countries reviewed, which result in disproportionate prejudice and pressure toward women when they are additionally affected by leprosy.

Traditional or religious societal beliefs about leprosy

Strong traditions, such as those summarised in four articles^{3,11-13} from Indonesia, Nepal and Brazil, present leprosy to have supernatural origins, such as a curse from God or ancestor for punishment of sins, or as the result of witchcraft. Where these historic traditions surround leprosy, the community stigma attached to those affected can be huge, yet these attitudes are not necessarily gender neutral. The above studies and others,^{4,14} including one in India, suggest that there is an expectation for women to visit a traditional healer before, if not solely, to cure the spiritual or traditional problem of leprosy. The extent of this finding varies throughout the articles, however there is a predominant impression, made explicit through one study in Indonesia,⁴ that women are more inclined to use religion or spirituality as a method of coping with societal stigma and finding solace

throughout the discrimination; although the literature is not conclusive how much more this is for women than men. Schuller *et al.*'s¹² study in Indonesia makes evident that women are never invited to attend community gatherings due to their fear of the affected person, yet the community had no problem with allowing access to religious meetings. Here, the message about leprosy was clear from the religious leader: it is not a curse, but a test from Allah, which can and should not be rejected by man.

Other reasons attributed to visiting traditional healers before a medical clinic, as described by the literature, include; the lack of confidence in western medicine and wariness of its effectiveness,² but also, as found by two studies in Brazil³ and India,¹⁵ the lack of knowledge surrounding the side-effects of MDT. De Oliveria³ in particular comments on the fear experienced by women in Brazil concerning the affect the treatment has on the appearance of the skin. The darkening of the skin is not only undesirable for women in terms of beauty standards, but also unwanted due to the social burden of required explanation.

Medical misconceptions about leprosy

Lack of information and communication surrounding leprosy, other false beliefs about how the disease can be contracted, and its incurability are common findings within the literature.^{1,11-13,16} Misinformation is found to often be the root cause of perceivably justified societal stigma, for example, that leprosy is hereditary, was a belief found in Indonesia. This misconception can drastically reduce women's marital chances, being dismissed by prospective spouses for fear of producing leprosy affected children; a finding not attributed to the experience of men.^{11,12} Fear of infection is another norm found to fuel societal stigma. Believing that simply sharing a meal or passing someone on the road who has ever been affected by leprosy, are examples of the extent to which leprosy is feared in many of the observed communities. All twelve articles comment, to varying degrees, on collective stigma's outcome of isolation and exclusion of patients from the community; demonstrating the cross-cultural acceptance of this behaviour.

Stigmatisation from families

The permissibility of this exclusion was found to be doubly demanding for women due to their role as mothers and providers, throughout the literature. Being excluded from the home, unable to even touch their own children and fearing what their children must think of them, are reported to be some of the most difficult aspects of external stigmatisation experienced by women, particularly in India,^{14,15} Indonesia¹² and Brazil.³ In research studies in Nepal Van't Noordende *et al.*¹⁷ and Try,¹⁸ describe the fear that women have of being in their community without ever having been married, or having experienced divorce, stating that being married is an important pillar of Nepali society. Van't Noordende *et al.*¹⁷ suggest that women were far more likely than men, to be deserted by their spouses on diagnosis. While Try¹⁸ goes on to explain the undesirability of divorce and its ability to degrade a woman's status in society. In one case study she demonstrates the choice women can be left with, between enduring the physical and verbal abuse of a husband and having to "return as a disgrace to my parents' house."

Dependence & Low Status of Women

The review identified that all but one of the included studies demonstrate how the status of women in India, Nepal, Ethiopia, Brazil and Indonesia can unequally burden women if they are to discover leprosy symptoms. The social burden of simply being a woman in these situations can result in unequal access to services, even if they are immediately available. Rao *et al.*'s¹⁴ study in India

found a clear gender disparate delay in initiating and continuing to administer formal treatment, observing that the low social status of women in India, directly results in the greater suffering for women. They reference extreme dependence and discrimination in every area of their lives as a defining characteristic of the poor situations in which women can find themselves.

Physical dependence on others

In India and Nepal, three studies present the difficulty women with low socio-economic status face if they wish to independently travel to treatment clinics or leprosy centres. John, Rao & Das⁵ suggest from their data in India, that women had to wait until their husbands or guardians felt it was necessary to go to hospital. Burathoki *et al.*'s¹³ study details how women's dependence on their husbands or in-laws for any decision affects their ability to have their wishes heard and acted upon. Acknowledging that men and women both attribute a mother-in-law as a daughter-in-law's worst enemy, they comment that some men confessed a women's virilocality is the principle reason for stigma to be applied to female patients more severely than males. Women in these situations are judged solely on their ability to produce healthy children and conduct domestic duties well, and if they are unable, it is understood that they are no longer necessary for the household. This opinion is very much brought to light within the detailed case studies in Try's research in Nepal. One man goes as far as to ask rhetorically; "if men refused to help her, then how could she survive? Men can survive with a small piece of cloth but female can't. Women suffer more... husband is everything for a wife."¹⁸ This dominance over critical decisions and household members, according to this study, allows men to retain more respect than women if they face the stigmatisation of leprosy.

Economic dependence on others

Additionally, the literature demonstrates that women studied were not only physically dependent on others, but also had to rely economically on others within the household. In Varkevisser *et al.*'s¹ analysis of the four studies from Nepal, Nigeria, Indonesia and Brazil, it was found in that in all four areas of research, men were far better off financially. Ramos *et al.*'s²¹ study in Ethiopia found that in their retrospective study of patient records, far fewer women had been admitted to the clinic with neuropathic skin ulcers, even though it is one of the most common results of leprosy. The authors suggest that the economic burden that comes with accessing the clinic and continuing the care for wounds could likely be ascribed to this finding. Kumar *et al.*² also attribute the actual or perceived cost of travel to their finding that, in their study area in Nepal, men were twice as likely to complete treatment as women. In Try's¹⁸ analysis of Maithili culture in Nepal, she notes how expected gender roles for men as wage earners and women as carers and home keepers are strictly upheld; and in accordance with these expectations, women affected by leprosy experience more restrictions on their daily activities due to this strict binary. John, Rao & Das⁵ propose that women affected by leprosy in India suffer more adversely than men directly due to this lack of autonomy and the financial constraints upon them.

Impoverishment through divorce

As previously mentioned, the literature makes explicit the risk women face with regard to their marital status on the detection or diagnosis of leprosy. In many countries such and India, Nigeria and Indonesia, it is still legal or traditional for one spouse to expect and be granted a divorce on the discovery of leprosy in the other, and as Idawani *et al.*¹¹ note, particularly when deformities begin to occur. Some of the reviewed articles consistently draw on this theme, detailing the unequal experience women face if they are diagnosed with leprosy before marriage, or in the event of a divorce if

diagnosis occurs afterwards. Disabilities and stigma surrounding the disease disproportionately affect women. Studies reviewed with a focus of marital relationships in India¹⁹ and Brazil³ found that women were more likely to be single, divorced or living without their partner. Due to the previous findings of women's dependence on men, both physically and economically, the literature goes on to illustrate how being debilitated from the family group or divorced places women in a very unstable social and economic position. In Vlassoff, Khot & Rao's study in India, women reported to having experienced pressure to leave the household more frequently than men. In societies where women's domestic work will constitute the majority of their economic contribution, the inability to complete tasks due to disability or stigma, can render women worthless to their families. As one woman exclaimed: "Why would they take us if our hands were wasted? They have married our hands which cook and clean and sweep!"¹⁵

Physical and sexual abuse

Due to the low status and disempowerment of the women within the communities included in this review; if they are unfortunate enough to live with a family who cannot accept the disease and do continue to stigmatize them, they may be left in a catch-twenty-two position. Either they choose to stay in the household where there may be emotional or physical abuse or neglect; or, leave and potentially be left with little to no livelihood opportunities by themselves. For the many women included within the reviewed research, this was not a particularly difficult decision to make. In Burathoki *et al*'s study¹³ in Nepal, even despite deformities, it was found that many spouses would remain loyal, although women more often than men. Three studies^{3,17,20} highlight the sexual experience of couples once the wife contracts leprosy. All three paper's findings agree that women experience less sexual freedom than men, particularly if they have leprosy. For example, in Nigeria, men have more freedom to abstain from sexual intercourse on the leprosy diagnosis of their wives, than women would if it was their husband who was diagnosed.²⁰ In Nepal and Brazil alike, more women affected by leprosy said they did not find sex an important part of their marital relationship, but their views were not considered important or taken into account by husbands. Women simply had to be ready when their husbands were ready. If they blankly refused to engage in sexual intercourse, their husbands enjoyed more freedom to engage in sexual activity elsewhere.^{3,17}

Limited mobility outside of the home

The expected gender roles of women to be good mothers and wives, presiding over child care and domestic duties, was found in two studies to be the main cause of women's limited mobility outside the household.^{5,18} John, Rao & Das⁵ describe that in India, women's access to medical facilities often depended on whether or they had the time to visit; having to complete their household chores before setting out and after their return. It was highlighted that frequently service points kept women waiting, conflicting with their domestic work and lowering their social worth. Varkevisser *et al*.¹ comment that in all four study areas (Brazil, Indonesia, India and Nigeria) men were much more mobile than women, and therefore more able to travel further distances without the pressure to return as soon as possible. Other prominent research²²⁻²⁴ outside of this review also points to the conclusion that women from low socio-economic background often have a much smaller pool of social contacts due to their limited mobility, resulting in far narrower social capital and inability to utilise the support or other resources a wider scope of contacts may be able to afford. Another finding which may also be linked to this social dependence is the educational status of women included within the research. Schuller *et al*.¹² suggest that disabilities and stigma surrounding women affected by leprosy in Indonesia directly resulted in lower educational levels. In Nepal and Brazil level of education was found to differ greatly between men and women. Low literacy rates among women or none at all,

combined with the heavy workload and young marriage age were attributed by Burathoki *et al.*¹³ to the poor knowledge and awareness of clinical signs of leprosy and its treatment. An alternative discussion from de Oliveira's³ study found that in Brazil, men affected by leprosy were able to leave employment if their disabilities restricted their work, whereas women were less able due to the necessity of the domestic economy. This gendered distinction would result in the difficulty for women to engage in any activities outside of the household, such as non-formal educational projects or programmes.

Inner-Wellbeing: Self-Stigmatizing Attitudes

The review identified eight primary sources which establish themes surrounding the self-stigmatisation and mental wellbeing of women affected by leprosy. These themes range from hints towards negative self-attitudes as a potential reason for late diagnosis, to conclusive findings indicating strong correlations between internalised stigma and unwillingness to disclose their presumed health status. Kumar *et al.*'s² article outlines the gender differences in factors associated with treatment completion in Nepal, and notes that completion behaviours may relate to factors such as accepting the condition as final and unchangeable, with no urgent need for treatment. This concept could relate to the earlier point surrounding the belief that the disease is a curse from a God, evil spirit or ancestor, however it may also be attributed to the notion that women in cultures such as Nepal don't view themselves as individuals, but as an integral part, if not the unassuming cornerstone, of the collective that is the family or household. This lack of attention to their own inner-wellbeing can increase stigmatizing attitudes of women towards themselves, lowering self-esteem and intrinsic worth as a human being.

Women as more susceptible to mental illness as a result of diagnosis

Peters *et al.*⁴ pick this concept up in more detail, considering narratives around concealment of leprosy in women in Indonesia. They studied 53 women and found that the women who had concealed their illness the most, more frequently reported feeling sadness, shame, low self-esteem and depression, and that these feelings often result in self-isolation. Following this, the authors observe that it is not enacted stigma of others which leads women to conceal their disease, but anticipated stigma, which may or may not be received in reality. Women who continued to conceal their disease due to this fear instead increased negative feelings, emotions and internalised stigma. De Oliveira³, Schuller *et al.*¹² and Rao, Augustine & Joseph¹⁹ all maintain the notion that women experience a much higher degree of self-stigmatizing attitudes. These studies pertain from Brazil, India and Indonesia respectively; however, all equally point towards the acknowledgement of lowered levels of self-esteem, guilt and anxiety for women as an outcome of a leprosy diagnosis. In Schuller *et al.*'s¹² study exploring the experience of women with disability in Indonesia, women with physical disabilities due to the late diagnosis of leprosy had a much higher amount of psychological problems compared to women with other disabilities. The women themselves remarked that they were too embarrassed to let other people see their disabilities, and that they preferred to stay inside away from others altogether when possible.

Anxiety over identity loss

Another issue highlighted by the literature is that of the loss of identity for women when they become unable to perform household duties. That disabilities relating to leprosy are able to impact gender-prescribed roles in the household is yet another cross-cultural observation. In Brazil, de Oliveira³ reports that women experience guilt when physical limitations are placed upon them to be

able to contribute to household activities such as cooking or looking after children. She notes that a woman's inability to fulfil family roles can result in emotional breakdown and a sense of being stripped of the attributes which they themselves deem as necessary in order to be a competent woman. Three studies from India and Nepal^{12,14,15} confirm this finding, attributing a limitation on family roles towards the decrease in self-esteem and self-worth as mentioned by other authors. One¹² suggests that women affected by leprosy feel guilt and shame when they are unable to contribute to the household, and another¹⁵ goes even further to attribute this redundancy to a cause for women to want to, on their own accord, leave the household altogether, causing potentially serious economic problems.

Gender Insensitivity of Services

The final theme addressed as a barrier to early case detection by the literature is the experience women may have had in relation to leprosy services. Eleven articles make reference to the inadvertent difficulties and constraints women may face when attempting to access professional help, due to previously mentioned tasks and roles expected of women; which may not have been taken into account by service providers. One aspect of this difficulty can be the physical infrastructure of leprosy clinics or services. Whilst not a female-specific issue, two articles noted that the lack of roads suitable for motor vehicles in order to provide access to leprosy services in remote regions of Nepal. When services are difficult to access, particularly in dry and rainy seasons, and when resources within services are basic at best, women may find it even more demanding to convince others to accompany them in their urgent time of need^{2,13}. Burathoki *et al.*¹³ also note that in Nepal, privacy for women within clinics was a problem, where it was reported that health facilities were so small that several activities had to take place in one room; unsurprisingly making patients reluctant to undress. Two studies from India^{5,19} echo the urgent need to ensure privacy during physical examinations, or female only bathrooms, as a way to ensure an acceptable standard of provision for women.

Staff-patient relationships

Staff-patient relationships are another aspect of leprosy services which must be considered through a gender lens, as relationships with the opposite sex are found in five articles^{2,5,11,13,20} to be a potential problem in the diagnosis of women affected by leprosy. In an overview of three studies in Indonesia, Nigeria and Nepal, Varkevisser¹ notes how male staff formed the majority in all three cases, yet even in pockets where women were overrepresented within staff, both sexes encountered difficulties approaching and investigating patients of the opposite sex. John, Rao & Das⁵ mention that of their study in India, given that 60% of women had delayed seeking medical care and concealed their disease, the need is urgent for services to be sensitive to the requirements of women through the employment of enough trained female staff. Interestingly, they also note, and are seconded by Kumar,² that the quality of the relationship between staff and patient is equally important in order to uphold the retention of women affected by leprosy within their treatment cycle. They recommend that ensuring enough time is given to each patient to listen to their individual problems and counsel them would ensure that patients are not disappointed or feel let down by the service.

Patient and family counselling

The inadequacy of patient and family counselling is mentioned within eight of the reviewed articles.^{5,11,13,15-17,20,21} Four studies from Indonesia,¹¹ Nepal,¹³ Brazil,¹⁶ and Nigeria²⁰ all report this inadequacy in services. Patients would receive some information about treatment and curability of

leprosy, but little to nothing about the symptoms, causes or infectiousness. This is particularly pertinent for women due to their intrinsic position within the family. If the family (the spouse and possibly in-laws) were to receive professional and comprehensive counselling about the implications of a leprosy diagnosis, women may be more empowered to continue to live freely without fear of discrimination from her own family, preventing many of the reported problems.^{5,17} The understanding that services do not provide family counselling after a diagnosis of leprosy could be a huge factor contributing to the decision process of a woman with leprosy debating engaging in treatment or not. As Vlassoff, Khot & Rao¹⁵ report from India; the indifference faced by women affected by leprosy from their families caused them great suffering. Providing information to families is of utmost importance in order to help them understand the crucial role they play in aiding patients to cope and recover, as well as minimalizing the risk of patients being debilitated.

Information, education & communication

Eight articles present information, education and communication to have a huge role to play in the elimination of community based stigma which surrounds leprosy.^{1,2,5,12-14,17} In the same vain as family counselling, educating the entire community about the realities of the disease is believed to be a vital role that leprosy services must adopt. The curability of the disease must be explained in more detail, and in the terms of the community in a culturally acceptable way,^{5,17} and with the participation of patients and ex-patients themselves.¹ Myths about the speed of improvement and side effects of taking MDT is an issue the literature repeatedly recommends need to be addressed. The lack of awareness about leprosy and being able to identify it, in one study, was a leading reason for the delay in initiating formal treatment among women in the research area in India.¹⁴

Improved education of health professionals

In some cases, the literature shows that it may not be the lack of potentially beneficial health education within the community, but the lack of adequate training about leprosy on the part of health professionals, which leads to a lack of leprosy diagnosis.^{1-3,15,16} Whether that be private or government doctors who have not received training on leprosy,¹⁶ or counsellors with little knowledge about the side effects of MDT,^{3,15} it is clearly beneficial to any person affected by leprosy (but particularly women who can face many other hurdles in diagnosis and treatment) that health professionals are robustly equipped to manage a leprosy diagnosis effectively from start to finish.

The inability of services to take into account the special needs of women, expecting them to have the same expectations and experience of services as men despite the very different way society treats them, clearly has an impact on the acceptability of these services. Gender bias is shown throughout the reviewed literature to have an important implication for detection, treatment and control of the disease, and should therefore be taken seriously when planning and monitoring health/education interventions.

Recommendations

This review has identified 15 publications pertaining from five countries which explore the experience of women affected by leprosy. The eleven which detail the shortcomings of leprosy services all touch on the need to urgently address gender-related issues within practice, in order to create an environment whereby women feel comfortable to report cases of leprosy in its early stages. The barriers described within the first three sections of this review all relate to the increased experience of stigma faced by women due to unequal expectations and roles placed upon them by the

societies in which they live. If services fail to address the increased burden of stigma which women may face due to a diagnosis of leprosy, we may never know how many women continue to suffer in silence. Ensuring the equal participation of both genders within leprosy services may not only improve the detection rate among women, but also create an environment whereby issues faced by men affected by leprosy are also acknowledged. The review summarises the following recommendations found within the literature:

- Increased leprosy service involvement in female empowerment interventions

Running alongside medical services, organisations working to promote early case detection among women in areas with a low ratio of female cases may benefit from further involvement in, or inter-agency working with projects which aim to promote female empowerment and their involvement in community projects such as self-help groups or income generating activities. Ensuring women are able to engage in family decision making and sustain whatever they may deem a good quality of life whatever the outcome of a diagnosis, is just as significant as ensuring they are able to receive good quality health care.

- Increased staff sensitivity to local gender roles and relations

Better gender-awareness is needed on the part of health professionals, in order to ensure behaviour does not deter women from seeking medical advice. An increased number of female staff, gender-sensitivity training, private examination and counselling rooms and a general level awareness of pertinent side-effects of MDT may be possible options for future interventions to ensure the issues pertinent to both genders are addressed in relation to each other.

- Better family and patient counselling

Ensuring the whole family is included within the treatment process may help to improve stigma experienced by women within the household, expelling myths and creating a sense of accountability to ensure the continuation of treatment; ousting potential feelings of self-stigmatisation among women; and guaranteeing that both men and women in the household are able to make known their experience and expectations of a leprosy diagnosis.

- Increased community awareness through leprosy information, education and communication initiatives

More interventions urgently need to prioritise disseminating wide-reaching information messages about leprosy in order to reduce stigma caused by myths and traditional expectations of those affected. Routes towards this may include working with religious community leaders to circulate factual information about leprosy, targeting issues faced specifically by women; or learning from and working with successful gender-aware HIV/AIDS educational interventions in areas where leprosy is prevalent.

Conclusion

As summarised throughout this review, there is clearly plentiful evidence for the very distinct way women experience a diagnosis of leprosy. In a literature review of interventions available to promote early case detection of leprosy, Nicholls, Ross & Smith⁶ note that it is outstanding that there are no specific interventions working to address these distinct issues, which demonstrates a gap

between research and practice. That said, the need for future research surrounding the specific experience of women affected by leprosy is pressing. In order to supply practitioners with a robust evidence base of the barriers faced by women in their own specific communities, research is needed to best tailor future interventions and ensure best practice. Much can be done to further the case for women affected by leprosy without increased expenditure, but by simply ensuring that the lessons are learned concerning how local culture can influence perceptions of women and to address their needs more effectively.^{5,18}

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