Original Article

Diabetes amongst Leprosy-Disabled People in Bangladesh: A Cross-sectional Survey

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Abstract

Background: *Diabetes and leprosy are chronic conditions for which patients need to practise self-care. Little is known about how patients manage such comorbidities in Bangladesh.*

Methods: *Leprosy disabled people in north-west Bangladesh were surveyed for diabetes. Random blood glucose levels were measured. Data on disability levels and body mass index were collected and diabetic subjects were interviewed about self-care for their disease.*

Results: *Of the 3573 people with leprosy-related disability surveyed, 97(2.7%) were previously diagnosed with diabetes. They were variously receiving treatment and advice from specialist clinic services or other sources; 65% were on regular medication and only 16% were attending clinic for review more frequently than once in 3 months. Other patients were not receiving regular treatment or medical attention for their diabetes. A random blood glucose done by finger prick test showed 51/97 had levels >11.0 mmol/l and 20/97 had levels >18.0 mmol/l. Their self-reported compliance with medical advice was low. Amongst leprosy-disabled people, not previously known to be diabetic, with random blood glucose >11.0 mmol/l, referred for further assessment. Another 47 cases were confirmed to have diabetes making total prevalence about 4% in this population.*

Conclusions: *The survey results suggest that routine screening for diabetes amongst people affected by leprosy should be considered and that special attention needs to be directed to the ability and motivation of people with leprosy related disability to manage their own diabetes self-care.*

Key words: *Bangladesh; disability; leprosy; random blood glucose; self-care; survey.*

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Introduction

Since a high proportion of those with chronic non-communicable diseases have more than one long-term health conditions, high-income countries show an increasing recognition of the problem of multi-morbidity.[1] In UK 14% people with diabetes mellitus (DM) had at least one other condition and percentage is higher in those with greatest deprivation.[2] In low/middle income countries the combinations of conditions may differ but the "management problem" is similar. Both for the clinician and for the patient combined management of two long term conditions can be very difficult.

There is recently an increasing frequency of diabetes in South Asia and in people of South Asian origin in the UK.[3] In developing countries like Bangladesh evidence-based guidelines as used in UK[4]are not widely practised, and clinicians do not always clearly state whether a patient has type 1 or type 2 diabetes. Whilst the majority of diabetic cases in Bangladesh seem to be more like type 2, with an insidious onset amenable to treatment by diet with or without oral drugs, their profile differs from that of the typical type 2 diabetic in higher income countries. In rural north-west Bangladesh, a high proportion of diabetic patients are of low body weight and physically active.

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The importance of self-management in diabetes is well-known; it is likely that there are greater difficulties for physically-disabled people and for those who are living below the poverty line.

A common cause of physical disability in Bangladesh is residual morbidity from past infection with leprosy (largely peripheral neurological impairment), as there is an unfortunate overlap between complications arising from diabetes and from leprosy, any person affected by both diseases will be at enhanced risk of trophic ulceration, neuro-osteo-arthropathy and visual impairment. As leprosy currently is more common amongst poor people, for those who have both leprosy and diabetes self-care is often complicated by their lack of resources or of social support.

This survey is the first part of a larger project aiming to identify and to empower people with both diabetes and leprosy-disability, enhancing their ability to manage both conditions despite their lack of material resources. Results of random blood glucose tests on the other leprosy-disabled people conducted in the survey will be presented elsewhere.

Methods

The work was carried out in Nilphamari, Rangpur, Thakurgaon and Panchgar districts of Bangladesh. This study was approved by the institutional review board of The Leprosy Mission International Bangladesh.

Study design

The study consisted of a cross-sectional survey of people known to have leprosy-related disability in 4 districts of north-west Bangladesh covering nearly 8 million people. For each study participant, a random capillary blood sample was taken and for those who already knew they had diabetes, a short interview was carried out to assess the persons' self-reported current experiences of management of their diabetes.

Population and sample

The survey was implemented by staff of The Leprosy Mission International Bangladesh, which works in cooperation with the national leprosy control programme, in the area served by Rural Health Programmes (RHP), a well-established leprosy control project dedicated to clinical and epidemiological research and Community Programmes, which offers rehabilitation services. Eligible people were those adults registered for annual disability follow up because they were known to have a disability or multiple disability arising from leprosy, either consisting of peripheral nerve damage and its consequences or visual impairment due to leprosy (WHO disability grade 1 or 2 at release from treatment or at diagnosis if still under multi-drug therapy). Although there are leprosy-disabled children, no one under 15 years old was enrolled. A list of eligible people was generated from the RHP computer database and supplemented by names of other leprosy-disabled people known to local clinic staff. Attempts were made to contact all such individuals via mobile phone, by home visits or when they attended clinics. Any who indicated their willingness to participate were enrolled for the study, whether or not they stated that they already knew they had diabetes.

In this region there are, at sub-district level, government primary health care facilities and in each of the 4 districts there are 1-2 specialist non-profit diabetic clinics run by the Diabetes Associations of Bangladesh, as well as numerous individual private medical practitioners with varying skill levels offering services at commercial rates.

Methodology

After updating the disability follow up list by deducting 816 who had died, 3578 eligible people with leprosy-related disability were identified and contacted. Among them, 3573 consented to participate in the study. Trained staff, with due respect for confidentiality, approached eligible people systematically. Individuals who gave informed consent were asked whether they were aware of having diabetes and if so how they were managing it, using a simple questionnaire in Bengali (which had been field-tested in a pilot study). Compliance was assessed by use of a simple scale of 0-10, where 0 indicated "no compliance" and 10 implied "full compliance". Their leprosy status was checked and recorded (duration of disease, multi-drug therapy received, level of disability and presence of any acute complications such as leprosy reaction or current consumption of steroids for reaction). Height and weight were measured for calculation of body mass index (BMI).

All leprosy-disabled people including the known diabetics were then asked to have a finger prick blood test for random blood glucose (RBG) measurement by hand held glucometer. Glucometers were regularly checked for accuracy. Staff were instructed to advise further assessment at a diabetic clinic for anyone with RBG >11.0 mmol/l (diabetic suspects) and to refer urgently anyone with RBG >18.0 mmol/l (level considered to present immediate danger to health). All those previously known diabetic cases were informed that they would later be invited to participate in an educational/empowerment intervention, along with any newly diagnosed diabetics detected in the survey.

Leprosy-related disability is classified as grade 0, 1 or 2 according to the standard WHO system[5] in which grade 0 indicates no disability and grade 1 represents anaesthesia or other non-visible disability of limbs. Grade 2 is given if there is visible disability of hands/feet (such as resorption or trophic ulcers) and if there is loss of vision (<6/60) or lagophthalmos. The maximum score at any one site is taken as the overall score. The Eye Hand Foot score (EHF) is a similar but more detailed scoring system[6] in which the scores for the 6 individual sites (2 hands, 2 feet, 2 eyes) are summated.

Analysis

Data collected in the field on paper sheets were transferred to an excel database by trained data entry clerks and analysed using MS Excel.

Results

Among the 3573 patients surveyed, 97 (2.7%) had diabetes. During the survey, another 47 cases were found to have diabetes making the prevalence of 4%. Leprosy characteristics of the patients are shown in Table I. Mean age of all leprosy patients was 54.2 years, patients with leprosy and DM were a bit older (mean age 55.5 years). Mean duration of leprosy and EHL score among all patients and patients with leprosy and DM were 19.7 years and 19.1 years and 3.2 and 3.5 respectively. Of these people, 19/97 had severe levels of disability with EHF score of 6-12. Only 19 out of 97 diabetic patients were overweight or obese, most had normal or below normal BMI. The majority of diabetic subjects had already completed their multi-drug therapy (MDT) for leprosy and only 15 recalled ever receiving steroids for leprosy reaction.

Amongst the 97 subjects, 69 were receiving care from a specialist diabetic clinic and 5 attended government facilities for diabetic care while 5 said they attended a private practitioner, 16 claimed to be receiving diabetes treatment from the leprosy hospital and 2 gave an answer of other or none.

When asked about frequency of attendance, 16 said they attended monthly and 24 quarterly for review but 16 attended only annually and 41 less often or not at all. In 13 cases they specified non-attendance was due to poverty. Regarding types of treatment, majority (55, 57%) were receiving oral antidiabetic drugs (OADs), 8

Table I. Leprosy characteristics of the patients (N=3573)

	Total subjects	Released from treatment*	Under treatment*	Disability grade 1	Disability grade 2	Pauci-bacillary	Multi-bacillary
All patients (N=3573)							
Male	2580 (72.2%)	2450 (95%)	130 (5%)	919 (35.6%)	1661 (64.4%)	708 (27.4%)	1872 (72.6%)
Female	993 (27.8%)	935 (94.2%)	58 (5.8%)	414 (41.7%)	579 (58.3%)	302 (30.4%)	691 (69.6%)
Patients with known DM (N=97)							
Male	66 (68%)	61 (92.4%)	5 (7.6%)	22 (33.3%)	44 (66.7%)	17 (25.8%)	49 (74.2%)
Female	31 (32%)	29 (93.5%)	2 (6.5%)	17 (54.8%)	14 (45.2%)	10 (32.3%)	21 (67.7%)

(8%) were taking both insulin and OADs and 3 (3%) were taking herbal medicines. Rest of the patients were not taking antidiabetic medications.

Amongst the 97 subjects, 46 claimed their compliance with medication was 50% or more, 45 said their compliance with recommended diet was 50% or more, only 2 claimed to have received advice on diet at the clinic they attended so it is unclear what was their source of advice. Those who attend the Diabetic Association clinics receive an illustrated booklet containing information on appropriate diets.

Of known diabetics, 46 (33 males and 13 females) had RBSL within the "normal" range (<11.1mmol/l). Conversely, 23 males and 18 females (39% of all subjects) had RBSL above what we considered an acceptable level (threshold ie >11mM/l). The number with BSL>18m mmol/l (the danger level at which immediate medical attention is recommended[7] is 11 men and 9 women (20% subjects). (Table III).

Out of the 97 subjects who all were known to have established leprosy-related disabilities, 46 said they had no current problem due to leprosy (see Table iv). The other 51 people mentioned many problems, the majority (94) of which seem to fall easily into 3 categories Regarding their diabetes, 77 of the 97 subjects said they had current problems due to it, which fell into 2 main groups, those likely to be due to long term or to short term control problems (Table IV).

The considerable overlap in terms of effects of peripheral neuropathy is noteworthy since in some cases the subjects may be attributing the nerve function impairment to the wrong disease but in practice the effects of leprosy and of diabetes are compounded. Even for an expert clinician it is difficult to distinguish how much of the sensory nerve damage is due to diabetes in a person known also to have had leprosy. The high frequency of reported symptoms that are suggestive of acute hyperglycaemia or hypoglycaemia is worrying.

When invited to make free comments about the difficulty of living with both leprosy-disability and diabetes, 35 subjects commented on the high costs of medication for diabetes and 78 commented on the high costs of blood tests for diabetic control. (Table v). Many subjects suggested that the leprosy organisations should also offer diabetes management services. Leprosy treatment and investigations are free of cost under the National leprosy elimination programme supported by various Non-Government Organisations, hence direct expense related to medication or tests for leprosy is not an issue. When the findings of this study were presented to representatives of the district diabetic associations, some were so moved by the plight of leprosy disabled people struggling to manage their diabetes, that they undertook to attempt to negotiate concessionary rates for disabled people attending their clinics.

Table II. Self-reported compliance

Self-reported Compliance												
	0	1	2	3	4	5	6	7	8	9	10	Totals
Drugs*	1	4	11	19	16	16	5	14	8	2	1	97
Diet*	1	4	8	21	18	15	11	13	3	3	0	97

(*number of subjects who specified each score in numerical scale of "poor=0 to good=10")

Table III. Random blood sugar levels for subjects known to have diabetes

RBSL	<4.	4.0-	5.0-	6.0-	7.0-	8.0-	9.0-	10.0-	11.0-	>=	Totals
(mmol/l)	0	4.9	5.9	6.9	7.9	8.9	9.9	10.9	17.9	18	
Male	0	1	6	8	9	3	2	4	22	11	66
Female	0	0	0	2	3	4	2	2	9	9	31

Table IV. Patient Reported Problems

Patient Reported Problems	Number times mentioned
-attributed to Leprosy	
• Peripheral neuropathy	Total 47
o Claw hand	7
o Foot drop	4
o Ulcer	20
o Anaesthesia of loss of sensation in feet	16
• 13	
• Eye problems	20
• "Leprosy reactions"	
-attributed to Diabetes	
• Peripheral neuropathy	Total 77
o Foot problems	4
o Ulcers	16
o Pain	35
o Numbness	5
o Burning	5
• Eye problems	18
• Miscellaneous	
o Blood pressure	2
o Headache	5
o Teeth problems	6
o Other	1
• ? Probable acute effects of poor blood sugar	Total 111
• control	10
o Hypoglycaemia	59
o Weakness	4
o Hunger	38
o Excessive urine	

Table V. Other comments related to living with diabetes and leprosy disability

Need diabetic service from RHP/CP	91
DBLM hospital should offer diabetic services	18
Medicine is expensive	35
Regular tests for diabetes are expensive	78
The clinic is far away	0

Discussion

Diabetes prevalence is increasing in the world[8] so inevitably prevalence of disability due to diabetes will increase, particularly where management is sub-optimal. Bangladesh ranks tenth in terms of national case load for adults with diabetes, having about 18% of the global burden of diagnosed cases.[8]

The Diabetic Association of Bangladesh estimates that up to 7% rural and 10% urban population[3] are affected by diabetes. In this survey we identified 97 people with a previous diagnosis of diabetes amongst a large cohort of leprosy-disabled people living in rural north-west Bangladesh. We estimate there are a further 47-50 previously undiagnosed diabetics as a result of the survey. In total that implies a possible 4.30% prevalence rate in this specific population which is high, but below levels reported[3] for the general population. This may well represent under-diagnosis in a population which tends to make less use of general health services and so is less exposed to opportunistic screening. We do not know any reason for an increased/decreased incidence of diabetes amongst leprosy-affected people except during the short periods of time when some of them need steroids for leprosy reaction (which mostly occurs within 2 years of diagnosis) and may suffer steroid-induced hyperglycaemia. These subjects were diagnosed leprosy on average 19 years ago (72 of them more than 5 years ago), so steroid use was unlikely to be a significant factor among them. However, we did not collect data on other medications in use by the diabetics at the time of their blood test. Although the majority of this population were poor, we did not formally assess socio-economic status. Any difference between these leprosy-affected and other non-leprosy-affected people in the region, in regard to diet, body mass index or other known risk factors for diabetes, is probably small (personal observation). In contrast to tuberculosis, leprosy is not known to be associated with diabetes.

There is very little epidemiological information available to identify major risk factors in specific to the Bangladeshi population. Factors such as diet change over past 50 years or arsenic in drinking water may be contributing to the escalating epidemic of diabetes in this country.[10]

Leprosy incidence has decreased in recent years (as judged by new case detection rate) and is now below the threshold for declaring it "eliminated as a public health problem" in this country, but there are still about 3000 new cases detected every year.[11] Precise figures are not available at national level, for the large residual burden of chronic leprosy-related disability in people who have already completed treatment with multidrug therapy. We estimate that country-wide there are at least 30,000 people with permanent disability from leprosy, since the RHP leprosy control units with good statistics recorded over past 30 years or more has about 4,500 such people on its disability registers, when its catchment areas contains only about 5% total national population but about 17% national leprosy case load (unpublished data).

When a disease is very common, as diabetes now is in South Asia, inevitably there will be some individuals who have diabetes as well as another chronic disabling disease. Although we do not suggest that either diabetes predisposes to leprosy or the reverse, the 2 diseases will interact in their effect on a person's life and his/her ability to successfully undertake self-management.

Very little attention has been given to estimating or understanding the co-incidence/co-prevalence of diabetes with leprosy. One survey in India found 15% *residents of a "leprosy slum colony"* were diabetic; their sample included 63/133 disabled[12].

By comparison in this study of disabled leprosy-affected people *living in the community* we found 2.71% known diabetics (97 individuals) and 47 previously undiagnosed diabetic cases, which we believe may still be an underestimate as there were many more subjects with elevated random blood sugar levels.

These subjects had high levels of leprosy disability (as indicated by mean eye-hand-foot score of 3.5) associated with a long duration of leprosy (average 19 years), which may have made it difficult for them to comply with advice on managing their diabetes.

The subjects who had prior knowledge of their diabetes reported a moderate level of compliance with medication and diet, but about 21% had evidence of poor control (RBS over 18.0 M Mol/l). We did not make any other objective assessment of compliance (e.g. by inspecting the medical records or the medication available in the house). As most of our subjects attended diabetic clinics only at very long intervals it is possible that better control could be achieved by more frequent consultations Since BMIs of most of these subjects were relatively low, they do not need to lose weight but more detailed enquiry may reveal scope for improving the composition of their diet.

The subjects' self-reported symptoms indicate that there might be a high prevalence of long term complications of diabetes (eye damage, nerve damage and possibly renal impairment) amongst these leprosy-disabled people.

Further study is needed to elucidate barriers to compliance. Subjects themselves frequently mentioned cost of drugs and of blood tests as hindering regular attendance, and some mentioned difficulty in travelling to distant clinics for specialist advice on diabetes. However there may be other more subtle factors at work such as the manner in which visibly-disabled people are received at a specialist clinic by staff who are unfamiliar with leprosy disability, any displeasure shown by other diabetic patients queuing for attention when they find leprosy-disabled people amongst them, or physical barriers to entering the clinics(such as steps without ramps).

Even if they attend clinics and receive advice, how easy is it for these disabled people (who are generally short of resources) to implement the advice in their own homes? Problems in purchasing or cooking suitable foods, and practical difficulties administering medication (e.g. using an insulin syringe with deformed and anaesthetic hands), are compounded by Social barriers within the family if other members of household lack understanding about diabetes or are unsympathetic. A sense of self-efficacy is as important as having been taught about self-care[13].

In phase 2 of our project we will explore such issues further in order to offer an educational interventions designed to enhance self-efficacy, and thus empower for better self-management.

Being a cross sectional survey which does not provide information on progress over time in individuals (with respect to their diabetes or their leprosy disability), is a limitation of the study. However, the large number of subjects and the very high proportion of eligible people who were tested (94.3%), is a strength of this study.

Conclusions

Consideration should be given to active screening for diabetes of people diagnosed with leprosy, either at start of MDT or at RFT, and offering appropriate education about signs and symptoms of diabetes. People who have both leprosy disability and diabetes may be at higher risk of diabetes complications as they may be less capable of management of diabetes (as a direct result of physical disability, or because of associated problems such as disempowerment/social marginalisation/ low health literacy/poverty). Further study is needed to elucidate problems encountered by such individuals and to assess interventions designed to empower them for better self-management.

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