Original article

Patterns of health-seeking behaviour amongst leprosy patients in former Shoa Province, Ethiopia

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Abstract: This case-control study sought to determine factors influencing the early reporting of leprosy patients to modern treatment units. The Cases were 31 patients presenting with WHO disability grade 2 while controls were 48 patients presenting with grade 0. More than three- quarters (77%) of the cases waited for longer than 1 year before going to a leprosy clinic, whereas only 60% of the controls had waited over one year. On finding their first symptom, 68% of the cases and 23% of the controls went to a traditional healer. Ex-leprosy patients were found to be important advisors for early treatment. Compared with patients who sought traditional treatment, those whose initial contact was with the general health services had better outcomes. Worsening of symptoms was the final motivation for many of the patients to move from the traditional healer to the leprosy clinic. There were no significant differences between cases and controls with regard to sex, occupation, education or ethnic group. The study showed the need for intensive health education using different strategies to improve voluntary self-reporting of early cases of leprosy. [*Ethiop. J. Health Dev.* 2000;14(1):43-47]

Introduction

Scientific studies have gone some way towards countering the misconceptions, stigma, and superstitions attached to leprosy. Many people, however, particularly in developing countries, have still not changed their beliefs and attitudes towards the disease and are reluctant to go to clinics for examination even after being diagnosed, many have difficulty in accepting the disease. This in turn may lead to more deformities which by themselves, bring about medical, social, and economic problems for the patients as well as for their community. The problems of broken homes and the intense social stigma associated with the disease create an aura of dread and horror, and cause much distress and unhappiness to patients and their families (1).

The very low health service coverage in Ethiopia with (less than 45% of the population living within an acceptable distance of a modernhealth care facility) (2) could also contribute to the high proportion of people going to traditional healers (65-80%) 3 such as holy-water, spiritual healers or herbalists, on experiencing the first symptoms. It may also cause late direct reporting to modern health institutions. It has been about three decades since the All Africa Leprosy and Rehabilitation Training Center (ALERT) launched its leprosy control programme in the study area, Shoa Province,central Ethiopa providing fairly accessible clinics. This, however, did not greatly change the beliefs and attitudes of the community. This is demonstrated by the fact that many new cases still report late for treatment, as (the statistics of the control programme shows that 17% of all new patients diagnosed have visible deformity and about 40% have some sensory loss)(4).

In case studies undertaken by students at ALERT, patients talk of visiting traditional healers, going to the holy water, and visiting general health clinics before seeking modern leprosy treatment. If these delays could be minimized, the disability rate on presentation would similarly be reduced. Studies on the social aspects of leprosy in Ethiopia are very

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few and not much is known about health-seeking behaviour amongst patients. The objective of this study is -therefore, to compare patients with disability and those without disability in their beliefs and health-seeking behaviour which possibly affect their disability status.

Methods

This is a case-control study conducted in the former Shoa Province, the ALERT leprosy control area. The Shoa Province has a population of 13 million and an area of 87,000 km. It is located in the central part of Ethiopia and has a high endemicity of leprosy. Approximately 1,000 new patients have been registered every year over the last few years. Based on the available resources for this study, from the existing 270 leprosy clinics in the area, 30 were randomly selected for visits by the interviewers. To minimise recall bias, all patients who had been diagnosed over the last 12 months in the 30 clinics were considered for the study. From these new cases, all patients with an initial WHO disability grade of 0 (with no disability) were deemed controls and all patients with disability grade 2 were cases. Patients with a WHO disability grade of 1 were excluded since they were the largest group and their non-visible disabilities were difficult to classify. This study is therefore a comparison between patients with established disability (within a year of diagnosis) and those with none.

A pre-tested questionnaire was used to collect the data by two of the authors with knowledge of local languages. The data were analysed using Epi-Info and Egret. The unadjusted odds ratios of having disability were calculated for all parameters, and also calculated on an adjusted (multivariate) basis within groups of parameters where confounding was likely. The relatively small number of patients (79) and number of factors involved precluded a single multivariate analysis over all the parameters studied.

Table 1: **Characteristics of 79 Ethiopian leprosy patients, showing the unadjusted and adjusted (multivariate) odds ratios of disability for each characteristic, central Ethiopia, 1996**

Parameter	Value	Cases (%) n=31	Controls (%) n=48	unadjusted analysis odds ratio	95%C.I.	Multivariate analysis Odds ratio	95% C.I.
Age group	<25 yrs	12(39)	29(60)	1.00		1.00	
	25-39 yrs	6(19)	10(21)	1.45	0.34-4.89	0.25	0.19-3.34
	≥40 yrs	13(42)	9(19)	3.49	1.18-10.3	2.01	0.16-25.2
Sex	male	21(68)	35(73)	1.00		1.00	
	female	10(32)	13(27)	1.28	0.47-3.44	1.10	0.25-4.79
Religion	Orthodox	17(55)	37(77)	1.00		1.00	
	other Christian	6(19)	7(15)	1.87	0.54-6.40	1.10	0.24-5.00
	Muslim	8(26)	4(8)	4.35	1.15-16.5	11.9	0.64-86.3
Ethnic group	Oromo	20(65)	27(56)	1.00		1.00	
	Amhara	6(19)	14(29)	0.34	0.19-1.77	0.64	0.12-3.39
	Other	5(16)	7(15)	0.96	0.27-3.40	0.40	0.05-3.09
Marital status	single	10(32)	28(58)	1.00		1.00	
	married	16(52)	15(31)	2.99	1.09-8.19	2.35	0.22-25.7
	divorced/widowed	5(16)	5(10)	2.80	0.67-11.8	6.67	0.41-110
Education	Illiterate	19(61)	30(63)	1.00		1.00	
	Read & write	3(10)	3(6)	1.58	0.29-8.65	1.00	0.09-10.3
	Schooling	9(29)	15(31)	0.95	0.35-2.59	2.15	0.50-9.14
Occupation	Farmer	23(74)	32(67)	1.00		1.00	
	Other job	2(6)	5(10)	0.56	0.10-3.12	2.39	0.16-36.1
	Not working	6(19)	11(23)	0.76	0.25-2.35	1.15	0.24-5.44
Walking time to Clinic	under 1 hour	8(26)	21(44)	1.00		1.00	
	Over 1 hour	23(74)	27(56)	2.24	0.83-6.00	5.18	0.97-27.6

Table 2: **History and consequences of the disease among 79 Ethiopian leprosy patients, showing the unadjusted and adjusted (multivariate) odds ratios of disability for each characteristic.**

Parameter	Value	Cases (%) n=31	Controls (%) n=48	unadjusted analysis		Multivariate analysis	
				odds ratio	95%C.I.	Odds ratio	95% C.I.
First symptom	skin patches	12(39)	28(58)	1.00		1.00	
	nodules	10(32)	16(33)	1.45	0.52-4.12	1.15	0.31-4.28
	other/multiple	9(29)	4(8)	5.25	1.35-20.4	2.65	0.54-12.9
Treatment on first symptom	modern	10(32)	37(77)	1.00		1.00	
	traditional	21(68)	11(23)	7.06	2.57-19.4	7.70	2.22-26.7
Time to treatment	under 1 year	15(48)	21(44)	1.00		1.00	
	>1 year	16(52)	27(56)	0.83	0.34-2.05	1.20	0.36-3.95
Initial advisor	relative/friend	23(74)	28(58)	1.00		1.00	
	other	8(26)	20(42)	0.49	0.18-1.31	0.55	0.13-2.31
Final reason for attending clinic	worse disease	12(39)	13(27)	1.00		1.00	
	heard advice	19(61)	35(73)	0.59	0.22-1.54	1.25	0.32-4.79
Final advisor	relative/friend	18(58)	23(48)	1.00		1.00	
	other	13(42)	25(52)	0.66	0.27-1.65	1.19	0.31-4.60
Causal belief before illness	hereditary	12(39)	15(31)	1.00		1.00	
	other	19(61)	33(69)	0.72	0.28-1.85	1.32	0.30-5.88
Treatment belief before illness	modern	4(13)	15(31)	1.00		1.00	
	traditional	27(87)	33(69)	3.08	0.91-10.3	3.51	0.75-16.5
Causal belief after treatment	germs	1(3)	7(15)	1.00		1.00	
	hereditary	11(35)	4(8)	19.3	1.77-210	14.8	1.17-186
	other	19(61)	37(77)	3.60	0.41-31.4	2.98	0.32-27.6
Thinking changed to modern	yes	20(65)	16(33)	1.00		1.00	
	no	11(35)	32(67)	0.28	0.11-0.71	0.31	0.09-0.97

Results

A total of 79 patients (31 cases and 48 controls) were interviewed. The mean time between diagnosis and interview was 4.3 months (standard deviation: 3.6). Patients with disability were more likely to be classified LL (9/31 v 7/48), though this difference was not significant.

The basic patient characteristics on a univariate basis are shown in Table 1. Age, religion, and marital status emerged as significant factors. In a multivariate analysis of the same factors, (i.e., with all factors adjusted for all others in the table), being a Muslim was the only factor to retain significance, although walking time to the clinic was close to significance.

Table 2 shows parameters relating to the course of disease, the patients knowledge of leprosy and parameters emerging as a consequence of the patients' disease, in the same format as Table 1. On this basis, the significant factors were initial symptoms and the choice of treatment on first symptom. Only the latter retained significance on a multivariate basis. Patients whose thinking about leprosy had changed towards modern beliefs during the course of their disease were also more likely to be disabled. The only significant factor among these in the multivariate analysis was persisting in a hereditary causal belief.

As expected, those whose marital status or work had been affected by leprosy were more likely to be disabled, as were those who persisted in a hereditary causal belief.

Discussion

Most leprosy cases do not have disabilities when the disease first appears. Many conditions leading to disability and deformity can be cured if action is taken at an early stage (5). This study suggests that disability onset is closely associated with patterns of health knowledge and care-seeking behaviour. Patients initially presenting with grade 2 disability are more likely to have initially been to traditional healers than controls (patients without disability) and many delayed modern treatment for more than three years. On finding the first symptom, the majority of the study population sought some sort of treatment. This is in contrast to a study done in South -West Ethiopia where 55% of people with self perceived morbidity said that they did nothing for their illnesses (6). However, when talking of their normal practice with other diseases, more cases than controls said that they did not do anything when they were sick. This "wait and see" mentality was common to both cases and controls. Low health service coverage (2) could be incriminated to contribute to this type of response. The "otherness" of leprosy has been noted by Young (7), who reported that the Amhara ethnic group had many physiological explanations for disease, but leprosy was not one of them and was seen as hereditary.

Religion persisted as a significant factor in the analysis, reflecting a much higher proportion of Muslims among the cases. The causality of this is unclear; it may reflect different patterns of seeking traditional health care by Muslims compared with Christians.

In many studies (8) distance has been found to be one of the factors influencing health service utilization, as was the case here. This finding re-emphasizes the need for improvements in health infrastructure, which would in turn, improve access to leprosy services. Cases were more likely than controls to eventually seek treatment because of worsening disease, a factor that is likely to be linked with the accessibility of services.

Sources of advice for leprosy patients seem important in relation to treatment and outcome. Among the 'other' category of advisors, a small number of patients had been advised by existing leprosy patients, and had a good chance of getting early treatment (OR 21.8).

From the data, the pattern of eventually coming for modern treatment depends on where the patient went for his first treatment. Those who had initial contact with general health services were referred and in many cases saved from disability, whilst those who went to the traditional sector went for further treatment only when the disease worsened or the treatment was obviously seen to be ineffective.

The relationship between culture and health related beliefs and behaviour is complex. Personal experience, family attitude and group beliefs interact to provide an underlying structure for decision making during illness (9). That stigma remains a huge problem in Ethiopia is brought out by the study. Pankhurst (10) notes that "lepers" were not traditionally segregated, but by the 19th century many had become attached to the courts of the rulers and were beggars. They were often "very insolent" and would abuse passing governors, who in accordance with local custom would ignore the abuse. The names for leprosy showed also the negative thinking about the disease, with continued references to ***komata*** and bad disease. These negative influences must affect the patients' beliefs in cure. If leprosy is seen as the worst disease and associated with social isolation, delaying diagnosis may appear to have short-term social advantages. The concern amongst the controls about being seen at the clinics illustrates this. For those with disability it is already too late and they do not care about being seen. Leprosy remains associated with disability and wounds in the minds of the majority of Ethiopians. There is also a belief that cure is not possible; "once a leper, always a leper" (11).

Although in some ways the findings of this study may seem discouraging to those trying to provide leprosy services, there is also much ground for optimism. Several of the important factors that emerge from the study point to the potential of effective health education for the control of leprosy. Patients presenting without disability were more likely to have sought treatment as a result of hearing advice, rather than due to worsening disease, suggesting that if more and better advice were available, further impact might be made on leprosy disability. More cases claimed that their thinking on leprosy treatment had changed, which is a further encouragement to the possibilities of health education, even if in these individuals it may reflect changes too late for their own benefit. A causal belief in germs was highly associated with controls, particularly after adjusting for other factors.

The basic messages from this study would therefore be the need to strengthen leprosy services, particularly in terms of accessibility for treatment, and in providing more effective health education messages to encourage patients towards early modern treatment and away from traditional remedies for this particular disease. In view of the limited geographical area of this study and the relatively small sample size, further research is also needed to characterise in more detail the health -seeking behaviour of leprosy patients in Ethiopia.

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