



Non-communicable disease clinics in rural Ethiopia: why patients are lost to follow-up

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Background: Providing medical care for non-communicable diseases (NCDs) in rural sub-Saharan Africa has proved to be difficult because of poor treatment adherence and frequent loss to follow-up (LTFU). The reasons for this are poorly understood.

Objective: To investigate LTFU among patients with two different but common NCDs who attended rural Ethiopian health centres.

Method: The study was based in five health centres in southern Ethiopia with established NCD clinics run by nurses and health officers. Patients with epilepsy or hypertension who were lost to follow-up and non-LTFU comparison patients were identified and traced; a questionnaire was administered enquiring about the reasons for LTFU.

Results: Of the 147 LTFU patients successfully located, 62 had died, moved away or were attending other medical facilities. The remaining 85 patients were compared with 211 non-LTFU patients. The major factors associated with LTFU were distance from the clinic, associated costs and a preference for traditional treatments, together with a misunderstanding of the nature of NCD management.

Conclusions: The delivery of affordable care closer to the patients' homes has the greatest potential to address the problem of LTFU. Also needed are increased levels of patient education and interaction with traditional healers to explain the nature of NCDs and the need for life-long management.

The majority of sub-Saharan Africans live in rural areas.¹ They often live in poverty and have a substantial and increasing burden of non-communicable diseases (NCDs); however, health care for NCDs in these rural areas is very limited.^{2–5} Available primary care is directed towards the prevention and treatment of infectious diseases or maternal/child health, while services for NCD patients are still largely restricted to the secondary or tertiary hospitals found in the larger towns and cities. It is difficult for rural patients to attend these hospitals because they cannot afford the costs of travel and accommodation. There is therefore an urgent need to decentralise care and integrate the management of NCDs into the primary health system. Over the past 20 years in Ethiopia, a NCD care system comprising clinics run by nurses and health officers in rural health centres has been developed.⁵ Effective control of many prevalent NCDs in these rural populations, such as epilepsy and hypertension,^{6,7} has been achieved with minimal financial burden to the health centres.^{8,9}

A major problem, however, has been a continuing high rate of loss to follow-up (LTFU) at the rural clinics despite patients living nearby.^{8–12} Although LTFU is a worldwide phenomenon, it has been particularly problematic in sub-Saharan Africa. Among epileptic patients in Ethiopia studied in 2005, 60% had defaulted from follow-up after 2 years, while for a similar group of hypertensive patients, 42% were lost over 30 months of follow-up.^{8,9} This problem has also been reported elsewhere in both Ethiopia¹⁰ and in Cameroon, where studies of nurse-led clinics report 1-year retention rates of between 14% and 26%.^{11,12} Such high LTFU rates are important as they threaten efforts to improve NCD care in these communities. However, the reasons have been poorly studied and little is known as to how retention rates could be improved.

Data from hypertension clinics in large referral hospitals based in urban centres suggest that factors such as age, knowledge about the disease, distance from the hospital and the presence of comorbidities are all predictors of patient adherence.^{10,13–15} Little is known, however, about the retention of hypertensive patients in rural populations, where the reasons are likely to be different. While financial difficulties, knowledge of the disease, poor social support, stigma and the occurrence of side effects have been identified as factors affecting adherence in epilepsy patients attending urban clinics,^{16,17} data concerning rural epilepsy patients are sparse, although there are suggestions that the determinants of LTFU in rural areas may be different. For example, a study of epilepsy patients in rural clinics in Ethiopia found that the principal problems were travel difficulties and a preference for traditional remedies,^{8,18} while in rural Zimbabwe, drug shortages and the distance from health facilities have been reported.¹⁹

We therefore carried out a detailed investigation of the reasons for poor patient retention in rural NCD clinics, focussing on two contrasting diseases: epilepsy and hypertension. Patients with epilepsy are mainly young and symptomatic, with a high probability of successful control, while hypertension is usually found in older age groups and patients are largely asymptomatic. LTFU patients were compared with those with the same conditions but who were treatment adherent.

STUDY POPULATION, DESIGN AND METHODS

Study area

The study was based at five health centres within a 55 km radius of Jimma town in the Oromia Region of

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Ethiopia—Assendabo, Agaro, Seka, Serbo and Nada—which provide health care for large surrounding rural populations. Each health centre serves a population of between 25,000 and 50,000. Nurse-led epilepsy clinics were established in 1998 and hypertension clinics in 2008. As has been described elsewhere,⁵ nurses were trained at special workshops and given a basic set of training materials, which included simplified reference manuals, clinical guidelines and treatment algorithms for diagnosis and treatment. Hypertension was defined as systolic and/or diastolic blood pressure that is consistently in excess of, respectively, 140 mm Hg or 90 mm Hg.⁶ The diagnosis of epilepsy was based on the clinical history as reported by the patient and a witness.^{9,20} New patients were able to begin appropriate treatment and were followed up at the health centre. Large numbers of patients are now being treated at these clinics.

Study design

The survey was conducted between January and August 2017. Clinic LTFU was defined as non-attendance from follow-up of >6 months. During the Ethiopian year 2008 (September 2015 to August 2016), 163 of a total of 1344 patients with epilepsy and 105 of 431 patients with hypertension registered at the five clinics stopped attending. We also recruited a sample of 113 non-LTFU patients with epilepsy and 98 with hypertension from the same clinics.

Health extension workers (community-based health workers) visited the patients' homes to determine the reasons for LTFU. After obtaining informed consent, a questionnaire was administered to the patient or their legal guardian. This was designed to obtain basic demographic and socio-economic information, including details of education, occupation, personal habits and living conditions, using questions we previously developed in rural Ethiopia.^{21,22} Key patient outcomes (whether the patients were still alive, had transferred to another clinic or hospital or lapsed from medical treatment) were ascertained. The questionnaire also included questions about disease symptoms and the reasons for clinic non-attendance. There were specific questions about the mode of travel to the clinic and details of the associated costs. The final section was de-

voted to the patients' beliefs regarding healing and their use of traditional healers and medicines. The same questionnaire was administered to the non-LTFU control patients, with the exclusion of the sections on the reasons for LTFU. The questionnaire was translated into the local language, Oromifa, and was field-tested before use. Interviewers were trained and supervised to ensure the consistency and accuracy of answers.

Ethics

Ethical approval was obtained from the Jimma University College of Health Science Institutional Review Board (Jimma, Ethiopia); all patients or their legal guardian provided signed informed consent.

Statistical analysis

Data were collected using pre-prepared paper questionnaires, which were double-entered into computer spreadsheets with appropriate data checks. Categorical and binary variables were compared using the χ^2 test (or, where appropriate, the Exact test); continuous data were analysed using the *t*-test or non-parametric tests, where data could not be transformed to normality. *P* < 0.05 were considered to be statistically significant.

RESULTS

Of the 268 LTFU patients, 147 (54.9%) were located and completed the questionnaire (83 with a primary diagnosis of epilepsy and 64 with hypertension). Of these, eight subjects died and nine moved away from the area. In addition, 10 were receiving treatment from nearby health centres, 21 from private clinics, 13 from the local hospital and 1 continued to take treatment from an unknown source.

Table 1 compares the demographic and socio-economic data from the remaining 85 LTFU patients (48 with epilepsy and 37 with hypertension) and from non-LTFU patient groups. The sex distribution among both LTFU and non-LTFU patients was similar; the LTFU patients with epilepsy were somewhat younger, and the mean age of hypertensive LTFU patients and non-LTFU patients were similar. It should be noted that LTFU hypertensive patients had significantly poorer living conditions than non-LTFU controls: more LTFU hypertensive patients had thatched rather

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TABLE 1 Demographic and socio-economic characteristics of a sample of LTFU patients with epilepsy or hypertension and non-LTFU controls in five rural health centres in the Jimma Zone of Ethiopia, 2017

	Epilepsy			Hypertension		
	LTFU <i>n</i> (%)	Non-LTFU <i>n</i> (%)	<i>P</i> value	LTFU <i>n</i> (%)	Non-LTFU <i>n</i> (%)	<i>P</i> value
Patients, <i>n</i>	48	113		37	98	
Male sex	28 (58.3)	61 (54.0)	0.61	19 (51.4)	47 (48.0)	0.73
Age, years, mean \pm SD	21.3 \pm 12.5	26.2 \pm 12.9	0.03	54.6 \pm 18.0	53.5 \pm 13.0	0.68
Illiterate	30 (62.5)	83 (73.5)	0.17	26 (70.3)	79 (80.6)	0.20
Thatched roof	15 (31.3)	30 (27.8)	0.66	13 (36.1)	9 (9.5)	<0.001
Animals sharing living space	9 (18.8)	24 (21.4)	0.70	8 (21.6)	7 (7.3)	0.03
Separate kitchen	30 (63.8)	74 (66.7)	0.73	23 (62.2)	80 (84.2)	0.006
People/room, mean \pm SD	2.2 \pm 1.4	2.3 \pm 1.5	0.95	2.0 \pm 1.0	2.0 \pm 1.2	0.97
Hunger season difficulties*	18 (37.5)	19 (17.3)	0.006	11 (30.6)	22 (22.4)	0.33

*Food deficits in the pre-harvest months. LTFU = lost to follow up; SD = standard deviation.

TABLE 2 Stated reasons for LTFU among patients with epilepsy and hypertension in five rural health centres in the Jimma Zone of Ethiopia, 2017

	Positive responses	
	Epilepsy <i>n</i> (%)	Hypertension <i>n</i> (%)
Patients, <i>n</i>	48	37
Lack of knowledge	7 (14.6)	7 (18.9)
Much improved health	24 (50.0)	22 (59.5)
No improvement	12 (25.0)	2 (5.4)
Failure to cure	9 (18.8)	2 (5.4)
Did not feel unwell	9 (18.8)	10 (27.0)
Cost of travel	13 (27.1)	13 (35.1)
Other travel-related factors	18 (37.5)	10 (27.0)
Unable to stop working	2 (4.3)	0
Drug side effects	3 (6.3)	1 (2.7)
Drug costs	6 (12.5)	16 (43.2)
Drugs not available	6 (12.5)	4 (10.8)
Service dissatisfaction	8 (16.7)	2 (5.4)
Prefer other treatments	12 (25.0)	4 (10.8)

LTFU = loss to follow-up.

than corrugated iron roofs, more shared living space with animals, or lacked a separate kitchen. Although trends in epilepsy patients were similar, but non-significant, this group also reported a significantly greater frequency of difficulties during the hunger season. LTFU epilepsy patients reported a higher frequency of seizures (70.2% reported a seizure frequency of >1 per month compared with 28.3% of the non-LTFU group); however, there were no significant differences in symptom frequency between hypertensive LTFU patients and the non-LTFU comparison group.

Table 2 shows the stated reasons for LTFU. The most common reason given by patients was that they felt much improved (50% of epileptics and 59% of hypertensive patients). Significant numbers said that they did not feel unwell (19% of epileptics and 27% of hypertensives). Additional important reasons were the cost of travel and travel-related difficulties (27% of epileptics and 35% of

hypertensives). Treatment costs were considerable for both groups.

Table 3 shows the factors distinguishing LTFU patients from non-LTFU patients. Both epileptic and hypertensive LTFU patients were much more likely to use traditional medicine. The most common forms were herbal medicines (26% of cases) and the use of prayer or holy water (18%). There were no differences in the prevalence of smoking and alcohol intake (the reported frequency of these was very low), but more LTFU patients reported the use of the stimulant drug *khat*. The need to use public transport was greater and travelling time was longer in both the epileptic and hypertensive LTFU patients (significant for hypertensives), resulting in a median time for a return journey of between 3 and 4 h. Finally, the LTFU patients reported significantly higher travel and clinic (mainly drug) related costs, of which the latter represented a major proportion of the household expenditure (Table 3).

DISCUSSION

Although community-based NCD care delivered by health officers or nurses is potentially an effective and cost-efficient method of delivering chronic disease care in rural communities, our study findings highlight the difficulties of follow-up, with an annual loss of 12% among patients with epilepsy and 27% among hypertensive patients. While these are similar to rates reported elsewhere, both within Ethiopia and in other countries in sub-Saharan Africa,^{18,23} non-adherence to antihypertensive treatment is a common (43–65%) and global problem; up to 84% of uncontrolled hypertensives have been shown to be non-adherent.²⁴

Few studies have attempted to trace patients who have been lost to follow-up, as locating patients in remote rural areas is difficult and very time-consuming. Our tracing rate of 55% is therefore a major achievement. Another strength of our study is the comparison with patients who were adherent. A key finding was that 30% of the patients who had apparently left the clinic were actually attending other health centres, private clinics or a local hospital. This highlights the problem that without good medical records and unique identifiers, patients may be registered more than once when they relocate or transfer care. The socio-eco-

TABLE 3 Factors associated with LTFU among patients with epilepsy and hypertension in five rural health centres in the Jimma Zone of Ethiopia, 2017

	Epilepsy			Hypertension		
	LTFU <i>n</i> (%)	Non-LTFU <i>n</i> (%)	<i>P</i> value	LTFU <i>n</i> (%)	Non-LTFU <i>n</i> (%)	<i>P</i> value
Patients, <i>n</i>	48	113		37	98	
Use of traditional medicine	27 (56.3)	15 (13.3)	<0.001	17 (45.9)	1 (1.0)	<0.001
Use of <i>khat</i> *	15 (31.2)	20 (17.7)	0.057	20 (54.1)	23 (23.5)	0.001
Mode of travel to clinic						
Walking/animal	18 (37.5)	59 (52.2)		15 (17.9)	69 (70.4)	
Public transport	30 (62.5)	54 (47.8)	0.09	22 (43.1)	29 (29.6)	0.001
Travel time, min, median [IQR]	120 [60–180]	90 [60–120]	0.17	90 [30–165]	60 [20–120]	0.02
Cost of travel, US\$, median [IQR]	0.86 [0–1.74]	0 [0–0.86]	0.008	0.43 [0–1.57]	0 [0–0.30]	0.002
Treatment cost, US\$/month, median [IQR]	2.26 [1.91–5.09]	0.70 [0.43–1.74]	<0.001	3.04 [1.46–7.39]	0.70 [0.43–1.22]	<0.001
Treatment costs, as proportion of mean monthly non-food expenditure,% [†]	19.5	6.0		26.2	6.0	

* Local addictive stimulant drug.

[†] Calculated on the basis of data in.²⁸

LTFU = loss to follow-up; IQR = interquartile range.

conomic data in Table 1 show that LTFU patients tended to be poorer than non-LTFU controls, as measured by a range of indices that we have previously used to assess poverty in Ethiopia.²¹ This finding emphasises the significant role that poverty plays in limiting access to health care and the need to provide health care that minimises out-of-pocket expenses for the poor.

When asked directly for the reasons for their LTFU, many patients stated that it was because they had improved or did not feel unwell. This was surprising, given that the LTFU epileptic group reported more frequent seizures than the control group. It is likely that some had misunderstood the nature of NCD treatment. A recurring problem in Ethiopia is that patients often come to the clinic expecting a cure and are disappointed when told that life-long drug treatment is needed to manage their disease.²⁵ LTFU patients were also found to use traditional medicine or khat more often than non-LTFU patients (Table 3). The most common varieties of traditional medicine were herbal medicines or the use of prayer or holy water, which were particularly used by patients with epilepsy as there is a widespread belief in the community that epilepsy is caused by evil spirits. Previous studies have shown that there is a large variety of belief systems in rural Ethiopia and that traditional healers vastly outnumber doctors and nurses.^{25,26} Many patients appear to prefer traditional treatments or may continue with traditional medicines or practices even when attending the NCD clinic, while others may move from one treatment type to another, a process which has been termed 'healer shopping'.²⁷ These factors underline the need for improved understanding of traditional beliefs and practices, as well as more culturally appropriate education about epilepsy and hypertension for patients at health centres to reduce LTFU and improve adherence to treatment.

Although NCD care has been decentralised to rural health centres near patients' homes, one of the most common reasons for LTFU was the difficulty experienced in travelling to the health centre. LTFU patients used public transport more often and had increased travel times, which were associated with higher additional expenses compared to non-LTFU patients. Costs were also a key determinant of LTFU among both patients with epilepsy and those with hypertension (Table 3). The median estimated monthly total costs were between four and six times higher in LTFU patients, of which treatment costs, primarily for medicines, represents the largest proportion. The amount spent on medicines were high in comparison with mean non-food household expenditure in rural areas: equivalent to US\$11.6/ month²⁸ (Table 3). Although a waiver system in Ethiopia permits access to free health care for those most impoverished, the system has problems due to low levels of awareness of the waiver system, difficulty in obtaining the necessary papers and abusing the system rules so that the poor may not actually be the ones who benefit from the system.²⁹ The high cost of treatment is more severe for poorer families and undoubtedly contributes to the finding that LTFU is associated with poverty (Table 1). Cost was also cited as the most important reason for treatment non-adherence in the Gondar study on LTFU in epilepsy patients.⁸ These findings show that the costs associated with NCD treatment even in rural clinics are a major disincentive to continued attendance. This suggests that successful NCD care will depend on the development of low-cost health care systems that are affordable by the rural poor and will reduce out-of-pocket expenditures.³⁰ Unless sustainable solutions are found, there is a risk that NCD services will fail to reduce the burden of chronic disease and be a costly exercise with very little impact and a poor return on investment.

Although our analysis was restricted to epilepsy and hypertension, the reasons for LTFU in these prevalent and contrasting con-

ditions are likely to be representative of other NCDs. We conclude that the delivery of low-cost, affordable care closer to patient homes would have the greatest potential to reduce loss from follow-up. One approach could be the use of community health workers and community drug distributors at the village level. This has been effective in the management of the human immunodeficiency virus infection and certain infectious diseases in sub-Saharan Africa,^{31,32} and has been used successfully in the treatment of epilepsy in west Uganda.³³ In Cameroon, low-cost interventions adapted to an environment of task shifting and nurse-led care (such as the use of treatment contracts and reminder letters) were shown to significantly improve retention rates.¹² This process would have to be combined with the provision of heavily subsidised or free drugs. It would also need increased levels of patient education and interaction with traditional healers to explain the nature of NCDs and the need for life-long management.

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OBJECTIF : La fourniture de soins de santé pour les malades non transmissibles (NCD) en Afrique sub-saharienne rurale s'est avérée difficile en raison d'une adhérence médiocre au traitement et de fréquentes pertes de vue (LTFU). Les raisons en sont mal comprises.

OBJECTIF : Etudier les LTFU parmi les patients atteints de deux NCD différentes mais fréquentes, utilisant des centres de santé ruraux en Ethiopie.

MÉTHODE : L'étude a été basée dans cinq centres de santé du sud de l'Éthiopie, disposant de services de NCD gérés par des infirmiers et des officiers de santé. Les patients LTFU atteints d'épilepsie ou d'hypertension et les patients témoins non-LTFU ont été identifiés et retrouvés et un questionnaire administré à la recherche des motifs de LTFU.

OBJETIVO: Se ha demostrado que la prestación de atención médica por enfermedades no transmisibles (NCD) en zonas rurales de África subsahariana es difícil debido a la baja adherencia terapéutica y las frecuentes pérdidas de pacientes durante el seguimiento (LTFU). Este fenómeno no es bien comprendido.

OBJETIVO: Investigar los pacientes LTFU con dos enfermedades no transmisibles diferentes, pero frecuentes, que acudían a centros de salud rurales de Etiopía.

MÉTODO: El estudio se llevó a cabo en cinco centros de salud en el sur de Etiopía, que contaban con una consulta de NCD a cargo de enfermeros y auxiliares médicos. En el estudio, se compararon los pacientes LTFU de la epilepsia o la hipertensión, con pacientes tratados sin interrupción por estas enfermedades; se localizaron los pacientes ausentes y se completó un cuestionario sobre las razones de la LTFU.

RÉSULTATS : Sur 147 patients LTFU qui ont pu être localisés, 62 étaient décédés, avaient déménagé ou fréquentaient d'autres structures de santé. Les 85 patients restants ont été comparés à 211 patients non-LTFU. Les principaux facteurs associés aux LTFU ont été la distance par rapport au centre de santé, les coûts associés et la préférence pour des traitements traditionnels ainsi qu'une mauvaise compréhension de la nature de la prise en charge des NCD.

CONCLUSION : La fourniture de soins abordables plus proches du domicile des patients offre le plus grand potentiel vis-à-vis du problème des LTFU. Il faut également accroître le niveau d'éducation des patients et améliorer l'interaction avec les tradipraticiens afin d'expliquer la nature des NCD et la nécessité d'une prise en charge à vie.

RESULTADOS: De los 147 pacientes LTFU que pudieron localizarse, 62 habían fallecido, se habían trasladado a otra región o acudían a otros establecimientos médicos. Se compararon los 85 pacientes restantes con 211 pacientes sin interrupción de su tratamiento. Los principales factores relacionados con la LTFU en el consultorio se referían a los costos y a la preferencia por los tratamientos tradicionales, además de la falta de comprensión acerca de las características del tratamiento de las enfermedades no transmisibles.

CONCLUSIÓN: El hecho de prestar una atención de salud asequible y más cercana al hogar de los pacientes ofrecería la mayor posibilidad de resolver el problema de las LTFU. También es preciso mejorar el nivel de educación de los pacientes y reforzar la interacción con los curanderos, con el objeto de explicar mejor las características de las enfermedades no transmisibles y la necesidad de un tratamiento de por vida.