**Revision 2**

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

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Short Title: Why patients default from NCD clinics

Word Count:2581

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**Abstract**

Objective: Providing effective medical care for non-communicable diseases (NCD) in rural sub-Saharan Africa has proved to be difficult because of poor treatment adherence and frequent loss to follow-up (LTFU). As the reasons are poorly understood, we have investigated LTFU in a rural Ethiopian community among patients with two contrasting, but common NCDs.

Method: The study was based in five health centres in southern Ethiopia providing services for surrounding rural populations where NCD clinics run by nurses and health officers were initiated in 1998. Samples of LTFU patients with epilepsy and hypertension were identified and traced through health extension workers. A questionnaire enquiring about the reasons for LTFU was administered to LTFU patients and non-LTFU, comparison patients.

Results: Of 268 LTFU patients, the current status of 147(54.9%) was ascertained. Of these 62 had died, moved away or were continuing medical care at other facilities. The remaining patients (48 with epilepsy and 37 with hypertension) were compared with 113 non-LFTU patients with epilepsy and 98 with hypertension attending the same clinics. The major factors associated with LTFU were distance from the clinic, associated costs and a preference for traditional treatments together with misunderstanding as to the nature of NCD management.

Conclusions: We conclude that the delivery of low cost, 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.

Key words: Hypertension, epilepsy, NCD clinics, rural, default, Ethiopia.

**Introduction**

Most sub-Saharan Africans live in rural areas.1 They are often poor and have a substantial and increasing burden of non-communicable disease (NCD), yet health care for NCD is very limited.2-5 Available primary care is directed primarily to the prevention and care of infectious disease and maternal/child health while NCD care is still largely restricted to tertiary or secondary care hospitals, mainly found in the larger towns and cities. It is difficult for rural patients to attend these because they cannot afford the costs of travel and accommodation. Consequently, there is an urgent need to decentralise care and integrate the management of NCDs into primary health care. Over the past 20 years in Ethiopia we have developed a system of NCD care in rural health centres based on clinics run by nurses and health officers.5 We have demonstrated effective control of many of the prevalent NCDs in these rural populations, such as epilepsy and hypertension, 6 7 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 clinics despite the 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, 60% had defaulted from follow-up after two years, while for a similar group of hypertensives 42% were lost over 30 months of follow-up.8 9 The problem has also been reported elsewhere in both Ethiopia10 and in the Cameroun, where studies of nurse-led clinics report one 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. Yet the reasons have been little 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 co-morbidities all predict patient compliance.10 13-15 Little is known, however, about retention of hypertensive patients in rural populations, where the reasons are likely to be different. In the same way, while urban clinics treating epilepsy patients identify the role of financial difficulties, disease understanding, poor social support, stigma and the occurrence of side effects,16 17 data concerning rural epilepsy patients are sparse, although there are suggestions that the determinants of LTFU 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, shortages of drugs, and the distance from health facilities were documented.19

We have therefore carried out a detailed investigation of the reasons for poor patient retention in rural NCD clinics, focussing on two contrasting diseases: patients with epilepsy, mainly young and symptomatic with a high probability of successful control, and patients with hypertension, usually occurring in an older age group and largely asymptomatic. The LTFU patients were compared with groups of patients affected by the same conditions but who had continued with clinic treatment.

**Study population, design and methods**

Study area

The study was based at five health centres within a 55km radius of Jimma town in the Oromia Region of 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 people. Nurse-led epilepsy clinics were established in 1998 and hypertension clinics in 2008. As described, 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 diagnosed by systolic and/or diastolic blood pressures consistently in excess of 140 mm Hg or 90 mm Hg respectively. 6 The diagnosis of epilepsy was based on the clinical history from the patient and a witness.9 20 New patients were able to begin appropriate treatment and were followed up in the health centre. Large numbers of patients are now being treated at these clinics.

Study Design

The survey was done between January and August, 2017. Clinic LTFU was defined as non-attendance from follow-up of more than six months. During the Ethiopian year 2008 (Sept 2015 to Aug 2016), at the five clinics, 163 patients out of a total of 1,344 patients registered with epilepsy had stopped attending compared with 105 of 431 patients with hypertension. In addition, we identified 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 socioeconomic information including details of education, occupation, personal habits and living conditions using questions we have previously developed in in rural Ethiopia,21 22 while ascertaining the key patient outcomes (whether the patients were still alive, whether they had transferred to another clinic or hospital or lapsed from medical treatment). It also included details about their 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 asked about the patients’ beliefs regarding healing and their use of traditional healers and medicines. The same questionnaire was administered to the non-LTFU comparison 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 consistency and accuracy of answers.

Ethics

Ethical approval was obtained from the Jimma University College of Health Science Institutional Review Board and all patients or their legal guardian gave signed informed consent.

Statistical analysis

Data collection was carried out with pre-prepared paper questionnaires which were double entered into computer spreadsheets with appropriate data checks. Categorical and binary variables were compared using χ2 tests (or where appropriate, exact tests) while continuous data were analysed using t-tests or non-parametric tests where data could not be transformed to normality. P-values <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 147, eight subjects had died and nine had 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 one continued to take treatment from an unknown source.

Table 1 compares the demographic and socioeconomic data from the remaining 85 LTFU patients (48 with epilepsy and 37 with hypertension) with the parallel data from the non-LTFU patient groups. The gender composition was similar in both the LTFU and non-LTFU patients and while the LTFU patients with epilepsy were somewhat younger, the ages of the hypertensive LTFU patients and non-LTFU groups were similar. Importantly, the LTFU hypertensive patients had significantly poorer living conditions than the non-LTFU comparison group; more had a thatched rather than corrugated iron roof, more shared the living space with animals, or lacked a separate kitchen. In addition to the trends being similar, although non-significant, in the epilepsy patients, this group also reported a significantly greater frequency of difficulties during the hunger season. The LTFU epilepsy patients reported a higher frequency of seizures, (70.2% reported a seizure frequency of >1/month compared with 28.3% of the non-LTFU group) but there were no significant difference in symptom frequency between the hypertensive LTFU patients and the non-LTFU comparison group.

Table 2 shows the stated reasons for LTFU. The most common reason given 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). Costs of treatment were important for both groups.

Table 3 shows the factors differentiating the LTFU patients from the non-LTFU comparison patients. Both the 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% of cases). There were no differences in the prevalence of smoking and alcohol intake (reported frequency of these was very low) but more of the 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 three and four hours. Finally, the LTFU patients reported significantly higher travel and clinic (mainly drug) costs; 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, the present study emphasises the difficulties of follow-up with an annual loss of 12% of the epileptic and 27% of the hypertensive patients. While these are similar to the rates in other reports both within Ethiopia and in other countries in sub-Saharan Africa, 18 23 non-adherence to antihypertensive treatment is a common (43% to 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 thus a major achievement. Another strength of our study is the comparison with patients who have remained in the clinics. 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 multiple registration of patients can occur when patients relocate or transfer care. The socioeconomic data in Table 1 show that LTFU patients tended to be poorer than the non-LTFU comparison patients as judged by a range of indices that we have previously used to assess poverty in Ethiopia.21 This finding emphasises the importance that poverty plays in limiting access to health care and the need for pro-poor health service provision that minimises out of pocket expenses.

When asked directly for the reasons for their LTFU, many patients stated that this was because they had improved or did not feel unwell. This was a somewhat surprising finding as the LTFU epileptic group reported greater fit frequency than the comparison patients. 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 lifelong drug treatment is needed to manage their disease.25 LTFU patients were also found to use traditional medicine or khat more often than the non-LTFU patients (Table 3). The most common varieties were herbal medicines or the use of prayer or holy water, which were particularly used by patients with epilepsy as the community has a widespread belief that epilepsy is caused by evil spirits. Previous studies have shown that there are a wide 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 while attending the NCD clinic while others may circulate between different forms of practitioner, a process which has been termed “healer shopping”.27 These factors underline the need for improved understanding of traditional beliefs and practices, and more culturally appropriate education about epilepsy and hypertension of patients at health centres to reduce default and improve adherence to treatment.

Although we have decentralized care for NCDs to rural health centres near patients’ homes, one of the most common reasons for LTFU was difficulty in travelling to the health centre. LTFU patients used public transport more often and had increased travel times which were associated with higher extra expense compared with the non-LTFU comparison patients. Costs were also a key determinant of default for both patients with epilepsy and hypertension (Table 3). The median estimated monthly total costs were between four and six times higher in the LTFU patients. Treatment costs were the major factor which were largely the costs of medicines; the amounts disbursed were high in comparison with mean non-food household expenditure in rural areas, 11.6US$ equivalent per month,28 as shown in Table 3. Although a waiver system in Ethiopia grants the poorest access to free health care, the system has problems due to low levels of awareness of the waiver system, difficulties in obtaining the necessary papers and gaming of the system rules so that the poor may not actually be the ones who benefit from the system.29 The high costs of treatment are more severe for poorer families and undoubtedly contribute to the finding in Table 1 that LTFU is associated with poverty. Cost was also cited as the most important reason in the Gondar study of LTFU in epilepsy patients.8 These findings show that that the costs associated with NCD treatment even in a rural clinic are a major disincentive to continued attendance. They suggest that successful NCD care will depend on the development of low cost health care systems that are affordable by the rural poor and which will reduce out of pocket expenditures.30 Indeed, 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 delivering very little impact and a poor return on investment.

Although our analysis has been restricted to epilepsy and hypertension, the reasons for LTFU in these prevalent and contrasting conditions are likely to be representative of other NCDs. We conclude that the delivery of low cost, affordable care closer to the patients’ 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 HIV and some infectious diseases31 32 in sub-Saharan Africa, and has been used successfully in the treatment of epilepsy in west Uganda.33 In a Cameroun trial, low-cost interventions suited to an environment of task shifting and nurse-led care (such as 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.

**Acknowledgements**

We are grateful to all the clinic patients who took part and the health extension workers who administered the questionnaire. We are particularly indebted to Ato Fuad who co-ordinated much of the study.

**Author Contributions**

YM, TD, AL, IF and DL developed the questionnaire, TD and DD supervised the data collection. The analysis was carried out by YM, DP and AM and the preparation of the manuscript by EP, DP, AM and DL. All authors have approved the final manuscript.

**Conflict of interest**: None

**Sources of Funding**: The Tropical Health Education Trust and the Medical Research Council.

Table 1: Demographic and socioeconomic characteristics of a sample of LTFU patients with epilepsy or hypertension and non-LTFU comparison patients in five rural health centres in the Jimma zone of Ethiopia, 2017.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | Epilepsy | |  | Hypertension | |  |
|  | LTFU | Non-LTFU | p-value | LTFU | Non-LTFU | p-value |
| No. of patients | 48 | 113 |  | 37 | 98 |  |
| Male (%) | 28(58.3) | 61(54.0) | 0.61 | 19 (51.4) | 47(48.0) | 0.73 |
| Mean age, yr. (SD) | 21.3(12.5) | 26.2(12.9) | 0.03 | 54.6(18.0) | 53.5(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 share 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 (SD) | 2.2(1.4) | 2.3(1.5) | 0.95 | 2.0(1.0) | 2.0(1.2) | 0.97 |
| Hunger season difficulties (%) | 18(37.5) | 19(17.3) | 0.006 | 11(30.6) | 22(22.4) | 0.33 |

LTFU: loss 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.

|  |  |  |
| --- | --- | --- |
|  | Number (%) of positive responses | |
|  | Epilepsy | Hypertension |
| Total number of patients | 48 | 37 |
| Lack of knowledge | 7(14.6) | 7(18.9) |
| Much improved | 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 miss farming | 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(2.5) | 4(10.8) |

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | Epilepsy | | | Hypertension | | |
|  | LTFU | Non-LTFU | p-value | LTFU | Non-LTFU | p-value |
| No. of patients | 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 khat\* (%) | 15(31.2) | 20(17.7) | 0.057 | 20(54.1) | 23(23.5) | 0.001 |
| Model 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 |
| Travelling time, minutes\*\* | 120(60,180) | 90(60,120) | 0.17 | 90(30,165) | 60(20,120) | 0.02 |
| Cost of travel, US$ eq. | 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$ eq./month\*\* | 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, % mean monthly non-food expenditure. | 19.5 | 6.0 |  | 26.2 | 6.0 |  |

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

LTFU: Loss to follow-up. \*local addictive stimulant drug \*\*Median (IQR)

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