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Rates of diagnosis and treatment of neurological disorders within a prevalent population of community-dwelling elderly people in sub-Saharan Africa

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Abstract *Background:* The prevalence of neurological disorders in those aged 70 years and over in the Hai district of Tanzania has been previously reported. The following research reports rates of patient's: treatment seeking, diagnosis and treatment within this prevalent population.

Methods: All people identified as having at least one neurological disorder in the prevalence study were questioned regarding whether they had sought treatment for their disorder, whether they had had a previous correct diagnosis and whether they were being currently treated.

Results: From a background population of 2232 people, 349 people had neurological disorders, of whom 225 (64.5%) had sought treatment for their symptoms. Of the 384 disorders identified in these 349 people, only 14.6% had been diagnosed and only

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9.9% were receiving appropriate treatment. Males were significantly more likely to have been diagnosed and were more likely to have been treated appropriately.

Conclusions: Levels of diagnosis and treatment were low, with some gender inequality. Reasons for this may include a lack of recognition of the condition within the local population and lack of access to appropriate services. In the absence of effective primary and secondary preventative measures, and effective treatment, the burden of neurological disorders is likely to increase with further demographic ageing.

1. Introduction

1.1. Neurological disorders in high-income countries

The annual economic cost of neurological diseases in Europe in 2004 has been estimated at €139 billion (US$ 180 billion) [1]. This estimate did not include direct non-medical costs (e.g. community care and informal care) and indirect costs. The World Health Organization (WHO) has launched a programme to scale up the treatment of people with neurological disorders [2]. The WHO states that even in high-income countries substantial treatment gaps exist, with up to half the patients affected by these conditions left untreated, and most neurological problems are dealt with by general practitioners and hospital physicians, rather than by neurologists.

Neurological disorders account for 10—20% of acute hospital admissions. Around 10% of the adult population consult their general practitioner each year with neurological symptoms, but less than 10% of these people are referred to hospital clinics. Developments in the management of neurological disorders are therefore relevant to doctors without specialist neurological training [3].

In the past 10 years, new treatments have become available for neurological disorders previously considered untreatable (e.g. multiple sclerosis, Alzheimer's disease, motor neuron disease). However, the high cost of these treatments has sometimes led to issues with health budgeting [3].

1.2. Neurological disorders in low- and middle-income countries

Unfortunately, no equivalent estimates on the financial cost of neurological disorders are available for low-income countries [4]. Nevertheless, there can be little doubt that such disorders represent a significant burden at an individual and societal level [5,6]. Furthermore, access to effective treatment is often hampered by lack of knowledge of medical conditions and by beliefs that such conditions are caused by evil spirits or witchcraft [6—8].

1.3. Aims and objectives

The age-adjusted prevalence of people aged 70 years and over with neurological diagnoses in the rural Hai district of Tanzania was previously reported to be 154.1 per 1000 (95% CI: 139.2—169.1) [9]. The primary aim of this study is to identify the proportion of people seeking treatment, diagnosed and on appropriate treatment for these conditions.

2. Methods

Ethical approval for the study was obtained locally from Tumaini University ethics committee and nationally from the Tanzanian National Institute of Medical Research.

2.1. Design

The methods for the prevalence study have been reported previously [9]. The data presented here relate to rates of treatment seeking, diagnosis and treatment of all those people identified as having a neurological disorder in the prevalence study.

2.2. Setting and study population

The study setting has been described previously and is only described briefly here [10]. The Hai district of northern Tanzania is located around Mount Kilimanjaro and includes a demographic surveillance site (DSS) in which there are regular population censuses. The most recent census was completed on 1st June, 2009. It reported the population of the 52 villages in the district to be 161,119, of whom 8869 were aged 70 years and over. Most villages have a small health centre or a dispensary for basic treatment. There are three small hospitals in the district, and a tertiary hospital in the adjacent district, Kilimanjaro Christian Medical Centre.

The goal of this study was to screen one-quarter of the DSS population. Therefore, 12 villages were selected (using a random number generator, with stratification to allow a representative spread of upland and lowland villages), with a total census population of 2425. Exclusions, refusals and additions have been reported previously [9]. The final cohort of participants was 2232 people.

2.3. Detection of neurological disorders and data collection

Data were collected between 1st November, 2009 and 31st July, 2010. The point prevalence date was the 1st January, 2010. Details of a screening instrument which we have developed and validated for neurological disorders in the elderly, was published in the Journal of Neurology. This instrument was used during the initial screening phase of the current study [10]. The sensitivity of the instrument was 87.8% and the specificity 94.9%. Participants were seen at a place of their convenience (village health centres or patients' houses). Signed informed consent was obtained from each participant. A thumbprint was obtained for those who could not read and write and the purpose and implications of the study were verbally explained. In cases where patients were unable to consent, written assent was obtained from a close relative. The neurology screening questionnaire was performed by a trained non-medical investigator (NMI). Age, sex, tribe, and level of disability (Barthel index score [11]) were also recorded. Severe disability was defined as a Barthel index score of <15 and moderate disability as a Barthel index score of 15—18. All positive responders were seen by the research doctor (FD) who performed a full neurological history and examination to confirm or refute the presence of a neurological disorder. Diagnoses of positive responders were assigned using the World Health Organization's (WHO) International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) [12]. Further specialist diagnoses were assigned as appropriate using internationally recognised standard diagnostic criteria. Details of all the diagnostic criteria used are given in the Appendix. Physiological tremor was not included. Headache had to be recurrent and affect the ability of the participant to perform their activities of daily living. All diagnoses were verified with a neurologist (WH) or a movement disorder expert (RW). Further details of the criteria used have been published previously [9].

All participants identified as having a neurological disorder were asked if they had sought treatment for their condition and whether they were currently being treated for it. Treatment seeking included visiting traditional healers and un-registered private pharmacies and dispensaries as well as more formal healthcare facilities. If patients responded that they were receiving treatment, the type and level of treatment was checked and recorded.

2.4. Statistical analysis

Confidence intervals (CIs) for prevalence and for odds ratios (OR) were calculated based on the assumptions of the binomial distribution. No attempt has been made to adjust our data for the effects of clustering of cases within villages.

3. Results

Of the study population of 2232 people, 1256 (56.3%) were female and 976 (43.7%) were male. There were 384 cases of neurological disorders amongst 349 people (35 people had two diagnoses). The age-adjusted prevalence of at least one neurological disorder was 154.1 per 1000 (95% CI: 139.2—169.1).

Of the 349 people with at least one neurological disorder, 64.5% had sought treatment for their symptoms. Of the 384 disorders, only 56 (14.6%) had been diagnosed correctly and only 38 (9.9%) had received appropriate treatment. A breakdown of these figures by sex is presented in Table 1 and by specific neurological disorders in Table 2. Males with a neurological condition were significantly more likely to be diagnosed than females (OR 2.05, 95% CI: 1.15—3.68). In cases where treatment was available in Tanzania, males were more likely to be treated, though the difference was not significant (OR 1.68, 95% CI: 0.85—3.32). The lack of significance in the latter result is likely to be due in part to the relatively small number of people being treated, representing a Type II error.

Overall, there was no significant difference in levels of disability between those who sought treatment and those who did not. Of 159 who did not seek treatment, 44 (27.7%) had moderate or severe disability, whilst of 225 who sought treatment, 67 (29.8%) had moderate or severe disability, OR 1.10 (95% CI: 0.71—1.74). Rates of treatment seeking and disability for selected neurological disorders are detailed in Table 3. For each specific disorder, the level of disability was not significantly associated with whether a person sought treatment or not. However, those disorders which were associated with the highest level of disability (epilepsy, stroke and Parkinson's disease) also had the highest levels of treatment seeking.

Table 1 Treatment seeking behaviour and rates of diagnosis and treatment of people with neurological disorders.

	Cases	Number who previously sought treatment (%)	Number with previous diagnosis (%)	Number with previous appropriate treatment (%)	Number for whom treatment exists (%)	Number for whom treatment exists in Tanzania (%)
Males	182 in 162 Males	109 (59.9%)	35 (19.2%)	21 (11.5%)	152 (83.5%)	143 (78.6%)
Females	202 in 187 Females	116 (57.4%)	21 (10.4%)	17 (8.4%)	188 (93.1%)	183 (90.6%)
Total	384 (in 349 Individuals)	225 (58.6%)	56 (14.6%)	38 (9.9%)	340 (88.5%)	326 (84.9%)

4. Discussion

To the best of our knowledge, this is the first published study of rates of diagnosis and treatment for neurological disorders in SSA from within a prevalent population. They reveal that although almost two-thirds of people with neurological disorders had sought treatment for their condition, less than one-tenth were on appropriate treatment.

4.1. Treatment seeking behaviour

Of the more common disorders, rates of treatment seeking for stroke, epilepsy and Parkinson's disease were high, whilst rates for tremor and headache were low. Although the reasons why treatment is sought for some conditions but not others are likely to be complex, the extent to which a condition is disabling appears not to be a significant factor. Previous researchers who have investigated treatment-seeking behavior in SSA have found that whether people seek medical treatment for their symptoms depends on a number of factors, such as access to services, financial issues, education level, social networks, intra-household power and health beliefs [5—8]. In the current study, rates of treatment seeking were similar for males and females. There is a growing need for effective interventions for many medical conditions in SSA. Further investigation of the factors which influence treatment seeking will help to inform strategies for the development of healthcare services in SSA.

4.2. Diagnosis and treatment

The majority of neurological disorders had not been diagnosed prior to the study. This was despite relatively high levels of treatment seeking. When patients sought treatment, it was often not in health centers and hospitals, but via un-registered private pharmacies and traditional healers. In these cases, an appropriate formal diagnosis was rarely made. Of the most prevalent disorders, stroke was the most likely to be diagnosed. Those who had been diagnosed were not necessarily treated, with just over two-thirds of those diagnosed receiving appropriate treatment. Those least likely to be receiving treatment when it was routinely available were patients with tremor disorders, and those most likely to be receiving treatment (secondary prevention) were those patients with a previous stroke. These generally low rates of diagnosis and treatment may partly reflect patterns of treatment-seeking behavior and health beliefs. However, in this resource-poor setting, it may also be due to a lack of access to formal healthcare.

The results of this study suggest some bias in rates of diagnosis and treatment for neurological disorders between men and women. There might be a number of reasons for this. First, in a society where healthcare is not free at the point of delivery, men are more likely to be the head of the household and have the final decision on financial matters [13,14]. When the male is the main provider of income, he must keep healthy and the health of a husband and the children is often prioritised over that of the mother. Women have different priorities in the home with the health of the husband and children coming above their own health [15]. Likewise, money for schooling and food for other family members often comes before the health of the mother [13]. Finally, women often hide symptoms if it reflects badly on their children or grandchildren and their suitability for marriage [16,17]. Such disparities are likely to be deep rooted in society and are present from early childhood in many cultures [18]. A study published in 2012 of 4822 people aged 18 years and over in Burkina Faso found a significantly higher prevalence of asthma, angina pectoris, back pain and joint disease in women compared to men [19].

People with neurological disorders in this population have been shown in this study to be significantly more likely to be disabled than people without neurological disorders [20]. Low diagnosis and treatment rates are likely to exacerbate the burden of non-communicable disease in SSA, a

Table 2 Treatment seeking behaviour and rates of diagnosis and treatment of people with neurological disorders split into specific disorders.

	Cases	Number who previously sought treatment (%)	Number with previous diagnosis (%)	Number with previous appropriate treatment (%)	Number for whom treatment exists (%)	Number for whom treatment exists in Tanzania (%)
Central nervous system disorders						
Movement disorders						
Tremor — all causes including cerebellar disease and Parkinsonism	110[*]	36 (32.7%)	6 (5.5%)	4 (3.6%)	103 (93.6%)	96 (87.3%)
Parkinsonism	14	10 (71.4%)	4 (28.6%)	3 (21.4%)	14 (100%)	14 (100%)
Cerebellar disorders	11[†]	5 (45.5%)	2 (18.2%)	1 (9.1%)	4 (36.4%)	4 (36.4%)
Other dyskinesias	5	0	0	0	5 (100%)	2 (20%)
Episodic and paroxysmal disorders						
Headache disorders	92	62 (67.4%)	4 (4.3%)	12 (13.0%)	92 (100%)	92 (100%)
Stroke	54	44 (81.5%)	36 (68.7%)	16 (29.6%)	54 (100%)	54 (100%)
Epilepsy	10	9 (90.0%)	2 (20.0%)	2 (20.0%)	10 (100%)	10 (100%)
Systemic atrophies/degenerative diseases affecting the central nervous system						
Motor neuron disease	2	2 (100%)	0	0	2 (100%)	0
Injury resulting in CNS dysfunction						
Spinal cord injury	5	4 (80.0%)	0	0	5 (100%)	0
Spinal cord dysfunction — other	0	—	—	—	—	—
Infection resulting in CNS dysfunction	0	—	—	—	—	—
Peripheral nervous system disorders						
Polyneuropathies	42	21 (50.0%)	3 (7.1%)	4 (9.5%)	42 (100%)	42 (100%)
Nerve, nerve root and plexus disorders						
Cranial nerves	14	14 (100%)	1 (7.1%)	0	4 (28.6%)	3 (21.4%)
Upper limb mononeuropathies	15	6 (40.0%)	2 (13.3%)	0	8 (53.3%)	8 (53.3%)
Lower limb mononeuropathies	5	4 (80.0%)	0	0	0	0
Plexus pathology	4	4 (100%)	1 (25.0%)	0	0	0
Root pathology	4	3 (75.0%)	0	0	3 (75.0%)	0
Inflammatory/infectious diseases of the peripheral nervous system						
Polio	5	5 (100%)	2 (40.0%)	0	0	0
Leprosy	1	1 (100%)	1 (100%)	0	1 (100%)	1 (100%)
Diseases of the myoneural junction and muscle						
Myasthenia gravis	1	0	0	0	1 (100%)	0
Muscle wasting and atrophy	17	11 (64.7%)	0	0	15 (88.2%)	13 (76.5%)

[*] Including cases of tremor due to parkinsonism/Parkinson's disease ($n = 12$) and tremor due to cerebellar disorders ($n = 11$) but not tremor due to stroke affecting the cerebellum ($n = 4$).
[†] Including cases of cerebellar disorders secondary to stroke ($n = 4$).

Table 3 Treatment seeking behaviour and level of disability for selected neurological disorders.

Disorder	Total number who sought treatment	Number with moderate or severe disability (Barthel index <15)		Odds ratio (95% CI)
		Treatment sought	No treatment sought	
Epilepsy (n = 10)	9 (90.0%)	8 (88.9%)	1 (100%)	0.52 (0.01—20.19)
Stroke (n = 54)	44 (81.5%)	28 (63.6%)	6 (60.0%)	1.17 (0.29—4.76)
Parkinson's disease (n = 14)	10 (71.4%)	6 (60.0%)	3 (75.0%)	0.50 (0.04—6.68)
Muscle wasting and atrophy (n = 17)	11 (64.7%)	7 (63.6%)	4 (66.6%)	0.95 (0.20—4.64)
Headache (n = 62)	32 (51.6%)	5 (15.6%)	9 (30.0%)	0.21 (0.06—0.68)
Peripheral polyneuropathy (n = 42)	21 (50.0%)	3 (14.3%)	5 (23.8%)	0.53 (0.11—2.59)
Tremor (n = 110)	36 (32.7%)	12 (33.3%)	15 (20.2%)	1.97 (0.80—4.81)

burden which is predicted to increase substantially as the population ages and the infection rates for communicable diseases, such as HIV/AIDS, tuberculosis and malaria, decline [21—23].

4.3. Limitations

The limitations of the initial neurological disorders prevalence study have been acknowledged [9]. The main additional limitation that relates to the current study is that a number of previous epidemiological studies have been carried out in the Hai district by this team of researchers over the last 10 years [6,24,25]. Consequently, rates of diagnosis and treatment may be higher than would be found otherwise. Specifically, those who had had a stroke were most likely to be receiving treatment to prevent recurrence. This may be partly a reflection of the educational work done by the Tanzanian Stroke Incidence Project, which ran from 2003 to 2006 [24]. Rates of secondary preventative treatment for stroke in other areas of SSA have been reported to be substantially lower [26].

5. Conclusions

This study has demonstrated low levels of diagnosis and treatment of neurological disorders in the community. Many neurological disorders can be treated readily and inexpensively. However, the reasons for these low rates are likely to be multifactorial and relate not only to availability and affordability in the broadest sense, but also to accessibility and cultural acceptability [8]. Identification and diagnosis of those with neurological disorders is clearly an important component in reducing the morbidity burden in SSA. It has recently been reported that African nations have very limited numbers of neurologists and geriatricians, with some countries having none [27,28]. As this situation is unlikely to change in the immediate future, other strategies to manage this burden should be sought. Since diagnosis must precede treatment, screening for neurological disorders by NMI is an important first step to improving treatment rates. Programs to raise awareness of medical conditions at a community level should be considered. In addition, the training of primary caregivers in the use of non-pharmacological interventions to manage such conditions should be considered. In the absence of initiatives to improve rates of diagnosis and treatment, neurological morbidity will continue to make a substantial, and increasing, contribution to the non-communicable disease epidemic in SSA [19].

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Contributions

Design/conception — Richard Walker, Felicity Dewhurst. Literature search — Richard Walker, Felicity Dewhurst. Data collection — Felicity Dewhurst, Matthew Dewhurst, Golda Orega. Data analysis — William K. Gray, Felicity Dewhurst. Interpretation of results — Richard Walker, William Howlett, Paul Chaote, William K. Gray, Felicity Dewhurst. Writing of paper and review — Richard Walker, William K. Gray, Felicity Dewhurst, William Howlett, Paul Chaote, Golda Orega.

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Appendix A

Criteria. used for the diagnosis of specific neurological conditions

- Essential tremor — Movement Disorder Society (MDS) [1], National Institutes of Health (NIH) [2], Tremor Research Investigation Group (TRIG) [3,4].
- Other tremors — Movement Disorder Society (MDS) [1].
- Parkinson's disease — UK PDS Brain Bank Criteria/Modified Hoehn and Yahr [5,6].
- Vascular Parkinsonism — Winikates criteria [7].
- Progressive supranuclear palsy — National Institute of Neurological Disorders and the Society for Progressive Supranuclear Palsy (NINDS—SPSP) [8].
- Stroke — The Oxford Community Stroke Project Classification (OCSP)/Bamford Classification [9].
- Tardive dyskinesias — American Psychiatric Association Task Force [10].
- Headaches — International Headache Society (IHS) [11—16].
- Epilepsy — International League Against Epilepsy (ILAE) [17,18].
- Motor Neuron Disease — National Institute of Neurological Disorders and Stroke (NINDS) [19].
- Spinal injury — American Spinal Injury Association (ASIA) [20,21].
- Myasthenia gravis — Myasthenia Gravis Foundation of America (MGFA) [22].

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