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Levels of functional disability in elderly people in Tanzania with dementia, stroke and Parkinson's disease

Kisoli A, Gray WK, Dotchin CL, Orega G, Dewhurst F, Paddick S-M, Longdon A, Chaote P, Dewhurst M, Walker RW. Levels of functional disability in elderly people in Tanzania with dementia, stroke and Parkinson's disease.

Background: Disability is associated with increasing age and poverty, yet there are few reliable data regarding disability amongst the elderly in low-income countries. The aim of this study was to compare disability levels for three of the most common neurological, non-communicable diseases: dementia, stroke and Parkinson's disease (PD).
Methods: We performed a community-based study of people aged 70 years and over in 12 randomly selected villages in the rural Hai district of Tanzania. Participants underwent disability assessment using the Barthel Index, and clinical assessment for dementia, stroke and PD.
Results: In a representative cohort of 2232 people aged 70 years and over, there were 54 cases of stroke, 12 cases of PD and estimated (by extrapolation from a sub-sample of 1198 people) to be 112 cases of dementia. People with stroke were the most disabled, with 62.9% having moderate or severe disability. Levels of moderate or severe disability were 41.2% in people with dementia and 50.0% in people with PD. However, the higher prevalence of dementia meant that, at a population level, it was associated with similar levels of disability as stroke, with 18.5% of 249 people identified as having moderate or severe disability having dementia, compared to 13.7% for stroke and 2.4% for PD.
Conclusions: Levels of disability from these conditions is high and is likely to increase with demographic ageing. Innovative, community-based strategies to reduce disability levels should be investigated.

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Keywords: Africa; dementia; disability; Parkinson's disease; stroke; Tanzania

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Significant outcomes

- People with stroke were the most disabled, with 62.9% having moderate or severe disability. Levels of moderate or severe disability were 41.2% in people with dementia and 50.0% in people with Parkinson's disease (PD).
- Although stroke cases were generally more disabled than people with dementia and PD, the relatively high prevalence of dementia means that, at a population level, disability rates are as high as for other conditions such as PD and stroke.
- Innovative, community-based strategies to reduce this burden should be investigated.

Limitations

- Although our findings are limited by the relatively small numbers involved, they support similar findings from other world regions and suggest that dementia, and dementia-related disability, is a major health concern in low- and middle-income countries as well as high income countries.
- The two-phase design of the dementia prevalence study did not allow direct comparison of disability levels between people with dementia, stroke and PD. As a consequence our results regarding disability in those with dementia are based on extrapolation.

Introduction

There are few data on the prevalence of disability and its association with chronic disease in sub-Saharan Africa (SSA), particularly among the elderly (1). This is despite the correlation between greater levels of disability, increasing age and increasing poverty. Disability levels are strongly associated with the ability to work, and in societies where little formal provision is made for retirement, the elderly are a substantial part of the workforce (2). The burden of disability on carers can be substantial. It can be disruptive to family life, with loss of income for the person with disability, and their carers, and increased psychosocial strain (3). In 2006, the United Nations highlighted the global importance of recognising and treating disability (4). The availability of high quality, internationally comparable and up-to-date data on disability is integral for the planning, implementation, monitoring and evaluation of inclusive healthcare policies.

Non-communicable diseases (NCDs) are becoming an increasing burden on health services in SSA (5–6). Yet health services in SSA are ill-equipped to deal with this increased burden, with few clinicians trained to identify NCDs in the community or in specialities such as neurology and geriatric medicine (7–8). In rural Tanzania, people with Parkinson's disease (PD) and dementia are largely undiagnosed and untreated (9–10). Furthermore, most stroke cases do not attend hospital (11), resulting in high early case-fatality and long-term disability in survivors (12–13).

We have recently reported on levels of disability in basic activities of daily living (ADLs) in a cohort of community-dwelling elderly people living in Tanzania (14). Here we report on the disability levels associated with individual chronic neurological, NCDs within this population. We were specifically interested in comparing disability levels in people with stroke, PD and dementia. We chose these conditions because they are relatively common neurological conditions and have recently been the subject of prevalence studies in Hai district (9,14).

Methods

Setting and subjects

Ethical approval for the study was obtained locally from Tumaini University ethics committee and nationally from the Tanzanian National Institute of Medical Research. This community-based study was conducted in a population living within a demographic surveillance site (DSS) in Hai district, northern Tanzania. The DSS was established in the 1990s as part of the Adult Morbidity and Mortality Project and is one of the longest established and best described DSSs in SSA (15). The site had a census population of 161 119 in June 2009, of whom 8869 were aged 70 years or over. The DSS covers 52 widely spread villages and is almost exclusively rural, with most adults working as subsistence farmers. Most elderly people continue to work on the farm until they are unable and few people are able to make financial provision for retirement.

The data presented here were collected as part of two concurrent prevalence studies conducted in the Hai district DSS, one focusing on neurological disorders in 12 randomly selected villages and the other on dementia in six randomly selected villages from within the 12. Both studies assessed people aged 70 years and over living in the villages. The method of case ascertainment and numbers of people identified and assessed is summarised graphically in Fig. 1. Data were collected between 1 November 2009 and 30 September 2010. All assessments were conducted in peoples' homes or a local meeting place (e.g. village hall or health facility), if more convenient for the participant. Assessments were carried out by a UK-based doctor employed by the study (F.D., S-M.P., A.L. or M.D.), assisted by a Tanzanian nurse (G.O. or A.K.) who also acted as translator.

The demographic characteristics of the randomly selected villages were broadly similar to those of the entire DSS. Of the background population of those aged 70 years and above (n = 8869), 4844 (54.6%) were females and 5690 (64.2%) were aged 70–79 years. In the 12 villages, 1256 (56.3%) were female and 1502 (67.3%) were aged 70–79 years. In the subset of six villages, 673 (56.2%) were females and 799 (66.7%) were aged 70–79 years.

Assessment and diagnosis for stroke and PD. Data on those who had had a previous stroke or who had PD were collected as part of the neurological disorders prevalence study (14). The study assessed all people aged 70 years and over living in the 12 villages, giving a study population of 2232 (25.1% of all people aged 70 years and over living in the DSS). The prevalence of stroke and PD was 24.2 per 1000 (95% CI 17.8–30.6) and 5.4 per 1000 (95% CI 2.3–8.4), respectively. Stroke was diagnosed according to the Bamford classification (16). PD was diagnosed according to the UK PD Society Brain Bank criteria (17).

Assessment and diagnosis of dementia. Dementia prevalence was studied in six villages randomly selected from the 12 villages in the neurological disorders study, giving a study population of 1198 people aged 70 years and over (9). Dementia was diagnosed according to the Diagnostic and Statistical

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Manual of Mental Disorders, fourth edition criteria (18). The dementia study had a two-phase design, with a stratified sample of 296 of the 1198 screened in phase I, fully assessed for dementia by a doctor in phase II. The two-phase design of the dementia prevalence study is in line with most other dementia prevalence studies in SSA conducted to date. Stratification was based on performance on cognitive screening (using the Community Screening Instrument for Dementia (CSI-D)) in phase I. We aimed to assess 100% of those with poor performance, 50% of those with moderate performance and 5% of those with good performance identified during the screening process. Seventy-eight cases of dementia were identified. After adjusting for the effects of stratification, the crude prevalence was 74.5 per 1000 (95% CI 60.1–89.7).

Background population

Data on disability rates in all 2232 people aged 70 years and over assessed as part of the neurological disorders prevalence study have already been published and are used here as a comparison group. Data for those with PD, stroke and dementia were removed to avoid double counting.

Assessment of disability

As part of both of these studies, data were collected regarding disability in basic ADLs, as measured by the Barthel Index (19). It has been assessed for validity and reliability in a wide range of populations and is used extensively to evaluate post-stroke function (20). It has previously been used to assess disability in Tanzania (12,21–23). For the purpose of this study we categorised scores according to the system proposed by Heslin et al. (24). A score of <15 indicated severe disability, 15–18 moderate disability and 19 or 20 mild/no disability. The climbing stairs item was replaced by climbing a steep hill, since most people living in Hai district do not climb stairs as part of their normal daily activities.

Statistical methods

In the dementia study, the phase II cohort was a stratified sample of the phase I cohort. Stratification was based on CSI-D cognitive screening performance, with over-sampling for those with poorer performance. The number of dementia cases in the six villages (the crude prevalence) was calculated by adjusting for the effects of stratification using the inverse of the sampling fraction. The crude prevalence was then used to estimate the number of dementia cases in the larger neurological disorders study cohort. Given the similarity in the demographic profile of the neurological disorders and dementia cohorts, no attempt was made to adjust for the effects of age and sex.

Chi-square tests were used to compare levels of moderate and severe disability to the background population. Since this involved multiple comparisons, the significance level was set at 1% to allow for inflation in the Type I error rate. Confidence intervals (CIs) for prevalence were calculated based on the assumptions of the binomial distribution. A lack of overlap in 95% CIs was taken as an indication of statistical significance.

Results

Disability levels in those with stroke and PD

We have previously reported that of the cohort of 2232 people aged 70 years and over studied in the neurological disorders prevalence study, 54 people (2.4%, 95% CI 1.8–3.1) were identified as having had a previous stroke and 12 people (0.5%, 95% CI 0.2–0.8) were diagnosed with PD (14). The recruitment process is summarised in Fig. 1. Disability levels for stroke and PD are shown in Table 1.

Disability levels in those with dementia

The recruitment process for the two-phase dementia prevalence study is summarised in Fig. 1. The dementia prevalence study identified 78 people with dementia from 1198 people screened in phase I and 296 people fully assessed in phase II. Twenty-four people who had dementia secondary to stroke and three people who had dementia secondary to PD were excluded from the group of people with dementia, since PD or stroke were likely to be the underlying condition, and a major factor in the development of dementia (25). Of the remaining 51 cases, 13 (25.5%) had severe disability and eight (15.7%) moderate disability, see Table 1. Of the 24 subjects with dementia secondary to stroke, 11 (45.8%) had severe disability and seven (29.2%) moderate disability. Those with dementia secondary to stroke were significantly more likely to have moderate or severe disability than those with dementia in the absence of stroke (χ^2 (1) = 7.48, $p = 0.006$).

Disability levels in the background population

From the background population of 2232 people, 2115 did not have a diagnosis of stroke, dementia or PD (see Fig. 1). Disability levels in the background population are shown in Table 1.

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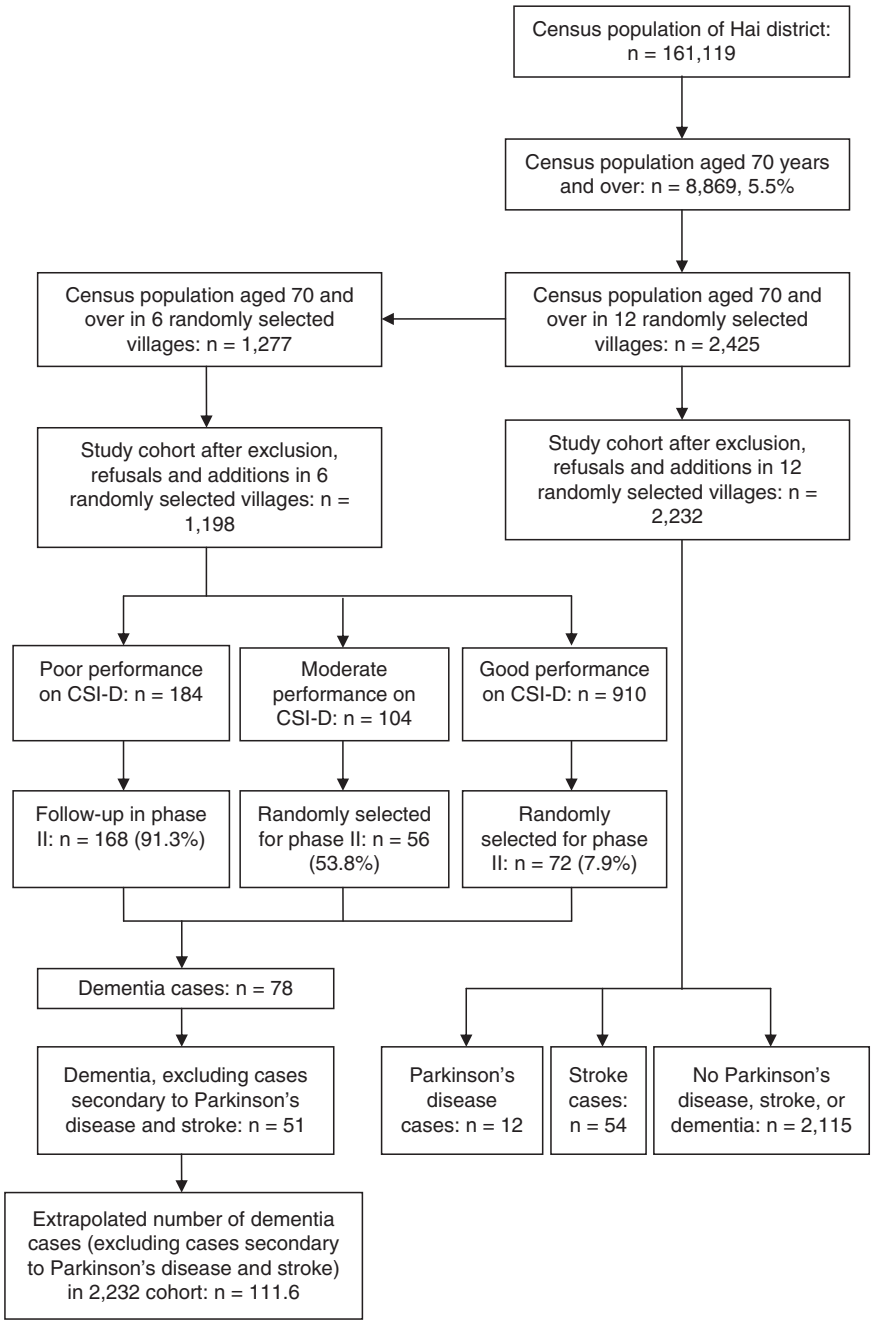

Fig 1. Case ascertainment methods.

Comparison of disability levels

Levels of moderate and severe disability are compared between the three disease groups and the background population in Table 1. All three groups had significantly higher rates of disability than the background population. The highest proportion of cases with moderate or severe disability was in those with stroke, followed by PD and dementia.

The two-phase design and smaller sample size for the dementia study does not allow a direct comparison with the data obtained from the neurological disorders study. However, it is possible to extrapolate from the available data to the larger study population of 2232 (see statistical methods section). Thus, we estimate that there were 111.6 dementia cases in the cohort of 2232 (see Fig. 1), with 28.5 (25.5%) having severe disability and 17.5 (15.7%) having moderate disability.

Within the cohort of 2322 people, 95 (4.3%) had severe disability, 154 (6.9%) had moderate disability and 1983 (88.8%) had mild or no disability (23).

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Table 1. Disability levels of cases of stroke, dementia, Parkinson's disease and the background population

	Stroke (n = 54)	Parkinson's disease (n = 12)	Dementia (n = 51)	Background population (n = 2115)
Mild or no disability	20 (37.0%)	6 (50.0%)	30 (58.8%)	1927 (91.1%)
Moderate disability	12 (22.2%)	3 (25.0%)	8 (15.7%)	131 (6.2%)
Severe disability	22 (40.7%)	3 (25.0%)	13 (25.5%)	57 (2.7%)
Significance of difference in number of people with moderate or severe disability compared to background population	χ^2 (1) = 167.58, $p < 0.001$	χ^2 (1) = 24.33, $p < 0.001$	χ^2 (1) = 59.55, $p < 0.001$	–

Of the 249 people who had moderate or severe disability, 34 (13.7%, 95% CI 9.4–17.9) had stroke, six (2.4%, 95% CI 0.5–4.3) had PD and we estimate that 46 (18.5%, 95% CI 13.7–23.3) had dementia. Thus, at a population level, the higher prevalence of dementia meant that it was associated with similar levels of disability in basic ADLs as stroke.

Discussion

This is the first published study to compare the role of specific neurological conditions on disability levels in an elderly population from SSA. Our results suggest that in Hai district, although community-dwelling people who have had a stroke are more likely to be moderately or severely disabled than those with dementia, the higher prevalence of dementia means that, at a population level, disability rates are similar for both conditions. Our findings in relation to dementia-related disability are in agreement with those of authors from other world regions (1,26–29). In the United States and Canada, dementia has been noted as strongly associated with the onset of functional dependency and the need for care home placement (26,28–29). Sousa et al. (1) found dementia to have the highest population-attributable prevalence fraction of a range of chronic diseases in people aged 65 years and over living in India, China and Latin America. Stroke had the next highest population-attributable prevalence fraction. Although there were 15 022 people from 11 sites in low- and middle-income countries included in the study, Africa was not represented. A study from Hong Kong (27) found dementia, stroke and PD to be the three most common sources of functional limitation.

We chose to focus our study on the prevalence of functional disability, rather than conduct assessments within a wider definition of disability that considered aspects such as social, psychological and mental health problems. The physical symptoms experienced by people with PD and people recovering from stroke are often obviously functionally disabling (12,30). In contrast, the functional disability associated with dementia can be less obvious. Dementia is often seen as a normal part of the ageing process in Tanzania and care is usually provided by younger family members within the home, a situation common in many low- and middle-income countries (31–32). In our experience, the level of care provided is generally good, despite limited resources. Our results suggest that, although this may be the case, functional disability attributable to dementia is common.

The low levels of disability seen in people with PD may be partly attributable to a programme of treatment for known cases of PD that had been recently initiated in Hai at the time of data collection (33). Before the treatment programme, historically high levels of mortality in those most disabled by PD, in part due to a lack of diagnosis and treatment, may also account for the low rates of disability. Furthermore, high rates of stroke mortality may mean that stroke survivors have generally had less severe, and less disabling, strokes than the general population of incident stroke cases (13). Stroke risk factor awareness may also have increased following a stroke incidence study conducted in Hai from 2003 to 2006 (11). However, in the short- to medium-term, this is unlikely to have had a substantial impact on stroke incidence and rates of post-stroke disability and case-fatality. At a population level, the profile of disability is likely to change as healthcare systems develop.

The main limitation of our study is that the design of the dementia prevalence study does not allow direct comparison of disability levels between people with dementia, stroke and PD. Those identified as having dementia were a stratified sample of those screened for the presence of dementia in phase I of the study and our results regarding disability are based on extrapolation. However, we have no reason to believe that those with dementia were unrepresentative of the wider population of people from Hai with dementia. Therefore, the extrapolation of disability data for those with dementia should not have resulted in any significant bias. We also recognise that the number of cases in each disease group is small. Finally, although functional impairment must be present for a diagnosis of dementia to be made, the levels of disability reported here are in excess of those required

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to make a diagnosis, thus any bias resulting from this is likely to be minimal.

Interventions to help reduce rates of disability-related dementia on communities in SSA are needed. However, before this can happen, those with dementia must be identified and diagnosed. Most people with dementia in SSA are living undiagnosed in the community and none of those identified in this study had been previously diagnosed. The burden of disability due to dementia can be high in this setting, not just for patients, but also for caregivers (3). The majority of people with dementia have no pension, and therefore no income, to contribute to the day-to-day running of the household. A further financial blow can occur where caregivers lose vital days at work to care for older relatives. Patients with dementia are unable to contribute financially but are also unable to contribute to the function of the family unit – not just an economic burden, a social burden. In this resource-poor setting, where government health budgets are already stretched, innovative ideas to improve rates of diagnosis of dementia together with effective intervention strategies to reduce disability levels should be sought (34).

Tackling risk factors, such as hypertension, may have an impact on the incidence of stroke and dementia. Interventions from allied healthcare professionals, such as support and education for patients and carers, may impact on disability levels, particularly in relation to stroke and PD.

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Conflicts of Interest

None.

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