



RESEARCH ARTICLE

Self-reported disability in rural Malawi: prevalence, incidence, and relationship to chronic disease [version 1; peer review: 1 approved with reservations, 1 not approved]

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V1 **First published:** 07 Jun 2019, 4:90
<https://doi.org/10.12688/wellcomeopenres.15196.1>
Second version: 03 Dec 2019, 4:90
<https://doi.org/10.12688/wellcomeopenres.15196.2>
Third version: 21 Oct 2020, 4:90
<https://doi.org/10.12688/wellcomeopenres.15196.3>
Latest published: 22 Dec 2020, 4:90
<https://doi.org/10.12688/wellcomeopenres.15196.4>

Abstract

Background: Disability is a complex concept involving physical impairment, activity limitation, and participation restriction. The Washington Group developed a set of questions on six functional domains (seeing, hearing, walking, remembering, self-care, and communicating) to allow collection of comparable data on disability. We aimed to improve understanding of prevalence and correlates of disability in the low-income setting of Malawi.

Methods: This study is nested in the Karonga Health and Demographic Surveillance Site in Malawi; the Washington Group questions were added to the annual survey in 2014. We used cross-sectional data from the 2014 survey to estimate the current prevalence of disability, simulate disability prevalence over the previous 12 years, and examine associations of disability with certain chronic diseases. We then reviewed the consistency of responses to the questions over time using data from the 2015 survey.

Results: Of 10,863 participants, 9.6% (95% CI 9.0-10.1%) reported disability in at least one domain. Prevalence was higher among women and increased with age. Since 2004, we estimate the number of people experiencing disability has increased 1.5 times. Obesity and diabetes were associated with disability, but hypertension and HIV were not. Participants reporting “no difficulty” or “can’t do at all” for

Open Peer Review

Reviewer Status

	Invited Reviewers	
	1	2
version 4 (revision) 22 Dec 2020		
version 3 (revision) 21 Oct 2020	 report	 report
version 2 (revision) 03 Dec 2019	 ? report	 X report
version 1 07 Jun 2019	 ? report	 X report

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any domain were likely to report the same status one year later, whereas there was considerable movement between people describing “some difficulty” and “a lot of difficulty”.

Conclusions: Disability prevalence is high and likely to increase over time. Further research into the needs of this population is crucial to ensure inclusive policies are created and sustainable development goals are met.

Keywords

Disability, Prevalence, Malawi, Africa, Chronic disease, Non-communicable disease, HIV, Health and Demographic Surveillance Site

Any reports and responses or comments on the article can be found at the end of the article.

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Competing interests: No competing interests were disclosed.

Grant information: This work was supported by the Wellcome Trust [098610], which supported both the HDSS census rounds and NCD survey.

The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

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How to cite this article: Prynne JE, Dube A, Mwaiyeghele E *et al.* **Self-reported disability in rural Malawi: prevalence, incidence, and relationship to chronic disease [version 1; peer review: 1 approved with reservations, 1 not approved]** Wellcome Open Research 2019, 4:90 <https://doi.org/10.12688/wellcomeopenres.15196.1>

First published: 07 Jun 2019, 4:90 <https://doi.org/10.12688/wellcomeopenres.15196.1>

Introduction

Disability is a complex and evolving concept. The prevailing framework for conceptualising disability is using the World Health Organization (WHO) International Classification of Functioning and Disease¹. Essentially, a person may have a health condition (e.g. diabetes) that can cause an impairment (e.g. visual impairment), which can lead to activity limitations (e.g. difficulties walking independently) and then to participation restriction (e.g. exclusion from employment). It is not inevitable that impairments will lead to participation restriction, and this will be mediated by personal factors (e.g. wealth, education, social support) and environmental factors (e.g. accessible buildings). People with disabilities, therefore, include those with long-term physical, mental, intellectual or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others². The WHO estimates that one billion people in the world have a disability – equating to one in seven people³. Of these, 110–190 million experience very significant difficulties in functioning. These numbers are expected to rise further as the global population continues to grow and average age increases. Disability is an important development issue, as the numbers affected are large, and people with disabilities face high levels of exclusion from different areas of life, such as school, employment, health and rehabilitation services³, and consequently are vulnerable to poverty⁴. It is unlikely, therefore, that the Sustainable Development Goals will be achieved without efforts to address participation exclusion among people with disabilities.

Global estimates are, however, largely based on extrapolations as data on disability are still relatively sparse. Moreover, there is wide variation in how disability is measured, such as whether the focus is on a specific impairment, or more holistically on participation and disability, and which tools are used. Consequently, it is difficult to compare data geographically, and over time. Consensus is growing on the use of the Washington Group (WG) Short Set to collect Disability Statistics⁵, to improve data comparability. The WG questions focus on difficulties in six functional domains related to activities (e.g. walking) and participation (e.g. performing usual activities). These questions are increasingly being used in censuses and national surveys, but have rarely been used in prospective studies, so few measures of incidence or persistence of disability exist. Existing demographic surveillance systems throughout the world offer an opportunity to help fill the large data gaps around disability, by measuring the prevalence of disability in a population living in a defined demographic area, who are followed over time. This follow-up will allow the assessment of the long-term impacts of disability, including on survival, as well as the consistency in categorisation of disability over time.

Exploring disability within the context of ongoing cohorts can also help to clarify other issues, such as the association between health and disability. The occurrence of disability, by definition, requires the existence of a health condition (e.g. stroke leading to physical impairment and ultimately social exclusion). People with disabilities may also be more vulnerable to poor health, as they may be poorer, have worse health behaviours, and

experience difficulties in accessing health services⁶. Furthermore, the underlying health condition (e.g. HIV) can directly lead to disability (e.g. via hearing impairment) as well as further health conditions (e.g. metabolic syndrome). The comprehensive data collected within demographic surveillance systems can help to clarify the drivers of the complex association between health and disability.

The objectives of this study were therefore to describe the prevalence, incidence and consistency in reporting of disability among adults in rural Malawi, and to describe the relationship between disability and chronic diseases in this cohort. Four disease markers were included to assess the association between disability and health: overweight and obesity, hypertension, diabetes, and HIV.

Methods

Setting and data collection

This study was based within the rural Karonga Health and Demographic Surveillance Site (HDSS), established in 2002 by the Malawi Epidemiology and Intervention Research Unit (MEIRU, formerly Karonga Prevention Study) in Northern Malawi. Annual censuses are taken of the population of around 42,000 individuals collecting data on demographic, social and health indicators. There is also continuous reporting on migration, births, and deaths by informants within the community. The population is largely a subsistence-farming and fishing community and has a similar age and sex distribution to the national rural population⁷. The WG short set questions were added onto the census in 2014 for individuals aged 18 and over. The six questions, which were translated into the local language of Chitumbuka, are:

- Do you have difficulty seeing, even if wearing glasses?
- Do you have difficulty hearing, even if using a hearing aid?
- Do you have difficulty walking or climbing steps?
- Do you have difficulty remembering or concentrating?
- Do you have difficulty (with self-care such as) washing all over or dressing?
- Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?

For readability, they will be referred to hereafter as difficulty seeing, hearing, walking, remembering, with self-care, and communicating. For each question the participant could choose one of four possible responses: no difficulty; yes, some difficulty; yes, a lot of difficulty; and can't do at all.

Although some HDSS census data can be collected when the participant is absent via a household proxy, the WG questions are only asked when participants are present (although they can be asked through a proxy, if the participant is unable to respond themselves, or by preference). Therefore, only those who were

at home on the day of the visit provided disability data. This analysis is of the disability data from two consecutive census rounds; the first was done from 2014 to 2015 (Round 1), the second from 2015 to 2016 (Round 2). Other data relevant to this analysis collected in the Round 1 survey included age, sex, education, occupation, marital status, and proxies of socio-economic status including access to a mobile phone, and household possession score (a composite score based on value of items owned by the household).

Data on hypertension and diabetes was available from a survey of non-communicable diseases (NCDs) in adults that was performed in 2013–2015, the methods of which are described elsewhere⁸. Blood pressure was measured three times, after 30 minutes' rest, with 5-minute rests between measures, and the mean of the second and third readings was used in the analysis. Fasting blood glucose tests were done in the early morning after a fast of at least eight hours. All data used from this survey was taken within 2.5 years prior to the Round 1 census date.

Body mass index (BMI) was also taken from the NCD survey unless data on height and weight was available from other studies in the same population obtained closer to the date of the Round 1 census. All studies used the same procedures to measure height and weight: both are measured twice, and BMI is calculated from the mean of these measures.

Data on HIV status was collected from multiple sources: a population HIV serosurvey completed in 2011; the NCD survey; and from consenting attendees at government antiretroviral therapy (ART) clinics within the HDSS.

Variables

Disability was defined as “a lot of difficulty” or “can't do at all” in at least one of the domains asked about, as recommended by the WG⁹. Educational attainment was grouped into; no formal education, primary education (including partially and fully completed), secondary education (including partially and fully completed), and tertiary education. Occupation was grouped into; not working, manual work (including unskilled and skilled work), farmer or fisher-man or -woman, or non-manual work (including unskilled and skilled work, professions, and businesses).

BMI was categorised as underweight (<18.5kg/m²), healthy weight (18.5-24.9kg/m²), overweight (25-24.9kg/m²), and obese (≥30kg/m²); hypertension as one or more of systolic blood pressure ≥140mmHg, diastolic blood pressure ≥90mmHg, or reported use of antihypertensive medication; and diabetes as a fasting blood glucose ≥7.0mmol/L or self-reported diagnosis of diabetes. HIV status was categorised as positive if the participant self-reported having ever had a positive HIV test, or negative if the participant had had a negative HIV test within 4 years prior to the Round 1 census date. Any negative HIV test of more than 4 years prior was counted as missing data, due to the possibility of a new HIV infection in the interim.

Statistical analysis

We calculated the prevalence of self-reported disability by socio-demographic background stratified by sex. As the age and sex distribution of the HDSS population over the previous 12 years was known, we applied our calculated age- and sex-specific prevalence estimates to the population structures at 4-year intervals since 2004, to simulate the change in absolute magnitude of self-reported disability over time.

We used multivariate logistic regression analysis to test for an association between BMI, hypertension, diabetes, and HIV with disability, and with each individual disability domain, controlling for age and sex. We sequentially added measures of socio-economic status including level of education, mobile phone use, and possession score to each regression model to check for confounding. No confounding was demonstrated, and these variables had substantial missing data, so we excluded them from the final models. Overweight and obesity are known risk factors for hypertension and diabetes, so in the final model we also controlled for BMI.

For those who also had disability data from Round 2, we examined the proportion whose disability status had changed between the two rounds. All analysis was done using Stata version 15.0 (StataCorp, College Station, TX).

Ethical approval

Ethical approval for the HDSS census rounds and NCD survey was granted by the National Health Sciences Research Committee (NHSRC) (protocol numbers #419 and #1072 respectively), and by the London School of Hygiene and Tropical Medicine (LSHTM) (protocol numbers #5081 and #6303 respectively). All participants gave written informed consent to participate.

Results

Of 17,987 adults included in the HDSS census of 2015 (Round 1), 10,863 (60.4%) participants provided data on self-reported disability; of those who did not, 28 were seen but missing data on disability status, and the remainder were not at home. In the Round 2 census one year later, 8,314 (76.5%) of these participants were interviewed, 112 had died, 634 had moved out of the area, and 1803 were not found at home, see [Figure 1](#). Men were more likely to have been missed in Round 1 (58.2% of men versus 24.0% of women), as were younger participants (43.1% of the 18–39 age group versus 16.9% of the 80+ age group), shown in [Table 1](#). Most participants were aged under 45 and there were twice as many women as men. The most common employment for both men and women was farming or fishing (77.7% women and 68.2% men). Overweight and obesity was more common in women than men, with 28.5% of women overweight or obese compared to 10.2% of men. 15.6% of participants had hypertension, 1.9% had diabetes, and 11.9% were HIV-positive.

Overall prevalence of self-reported disability was 9.6% (95% CI 8.1-10.1%). The most common disabilities reported were difficulty walking at 4.5% (95% CI 4.1-4.9%) and difficulty

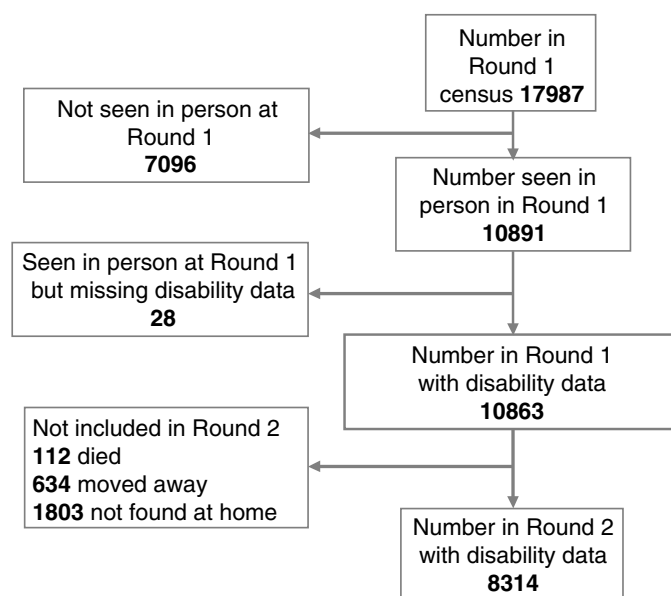


Figure 1. Flow chart of number of individuals participating in each round of the study.

Table 1. Baseline characteristics of participants with disability data at Round 1.

	Female		Male		Total	
	Census (n=9786)	Study (n=7437)	Census (n=8201)	Study (n=3426)	Census (n=17987)	Study (n=10863)
	n (%) ¹	n (%)	n (%)	n (%)	n (%)	n (%)
Age group						
18–34	5146 (52.6)	3817 (51.3)	4478 (54.6)	1545 (45.1)	9624 (53.5)	5362 (49.4)
35–44	1876 (19.2)	1478 (19.9)	1599 (19.5)	711 (20.8)	3475 (19.3)	2189 (20.2)
45–54	1105 (11.3)	814 (10.9)	935 (11.4)	443 (12.9)	2040 (11.3)	1257 (11.6)
55–64	781 (8.0)	606 (8.1)	552 (6.7)	306 (8.9)	1333 (7.4)	912 (8.4)
65–59	280 (2.9)	213 (2.9)	192 (2.3)	105 (3.1)	472 (2.6)	318 (2.9)
70–74	197 (2.0)	173 (2.3)	142 (1.7)	101 (2.9)	339 (1.9)	274 (2.5)
75–79	201 (2.1)	165 (2.2)	154 (1.9)	96 (2.8)	355 (2.0)	261 (2.4)
80+	200 (2.0)	171 (2.3)	149 (1.8)	119 (3.5)	349 (1.9)	290 (2.7)
Missing	0	0	0	0	0	0
Education						
None	378 (3.9)	296 (4.0)	104 (1.3)	69 (2.0)	482 (2.7)	365 (3.4)
Primary (part or completed)	6328 (65.1)	4980 (67.4)	3967 (48.6)	1833 (53.7)	10295 (57.6)	6813 (63.1)
Secondary (part or completed)	2529 (26.0)	1759 (23.8)	3449 (42.2)	1265 (37.1)	5978 (33.4)	3024 (28.0)
Tertiary	480 (4.9)	351 (4.8)	646 (7.9)	247 (7.2)	1126 (6.3)	598 (5.5)
Missing	71	51	35	12	106	63

	Female		Male		Total	
	Census (n=9786)	Study (n=7437)	Census (n=8201)	Study (n=3426)	Census (n=17987)	Study (n=10863)
	n (%) ¹	n (%)	n (%)	n (%)	n (%)	n (%)
Occupation						
Not working	1152 (11.9)	621 (8.4)	1503 (18.4)	391 (11.5)	2655 (14.9)	1012 (9.4)
Manual work	130 (1.3)	89 (1.2)	1084 (13.3)	387 (11.3)	1214 (6.8)	476 (4.4)
Farmer/ fisherman	7206 (74.4)	5721 (77.7)	4643 (56.8)	2327 (68.2)	11849 (66.4)	8048 (74.7)
Non-manual work ²	1192 (12.3)	930 (12.6)	939 (11.5)	309 (9.1)	2131 (11.9)	1239 (11.5)
Missing	106	76	32	112	108	88
Union status						
Not in a union ³	3383 (34.6)	2343 (31.5)	2637 (32.2)	870 (25.4)	6020 (33.5)	3213 (29.6)
In a union	6395 (65.4)	5090 (68.5)	5552 (67.8)	2553 (74.6)	11947 (66.5)	7643 (70.4)
Missing	8	4	12	3	20	7
BMI (kg/m²)⁴						
<18.5 (underweight)	622 (7.1)	481 (7.1)	643 (9.6)	298 (10.1)	1265 (8.2)	779 (8.0)
18.5–24.9 (healthy weight)	5650 (64.9)	4335 (64.4)	5407 (80.9)	2363 (79.8)	11057 (71.9)	6698 (69.1)
25–29.9 (overweight)	1771 (20.4)	1401 (20.8)	550 (8.2)	266 (9.0)	2321 (15.1)	1667 (17.2)
30+ (obese)	659 (7.6)	519 (7.7)	83 (1.2)	35 (1.2)	742 (4.8)	554 (5.7)
Missing	1084	701	1518	464	2602	1165
Hypertension⁵						
No hypertension	6288 (85.8)	4874 (85.3)	4641 (86.3)	2026 (82.4)	10929 (86.0)	6900 (84.4)
Hypertension	1041 (14.2)	837 (14.7)	737 (13.7)	434 (17.6)	1778 (14.0)	1271 (15.6)
Missing	2457	1726	2823	966	5280	2692
Diabetes⁶						
No diabetes	6401 (98.2)	4990 (98.3)	4536 (98.2)	2057 (97.5)	10937 (98.2)	7047 (98.1)
Diabetes	117 (1.8)	87 (1.7)	81 (1.8)	53 (2.5)	198 (1.8)	140 (1.9)
Missing	3268	2360	3584	1316	6852	3676
HIV status⁷						
Negative	6678 (88.1)	5134 (87.7)	4971 (90.4)	2164 (89.0)	11649 (89.1)	7298 (88.1)
Positive	902 (11.9)	719 (12.3)	527 (9.6)	267 (11.0)	1429 (10.9)	986 (11.9)
Missing	2206	1584	2703	995	4909	2579

1. Column percentages do not include those with missing data

2. Including those working in trade and professionals

3. Including never married, divorced, and widowed

4. Calculated from the most recent height and weight measurements (all taken within the past 2.5 years).

5. Defined as hypertension if self-report of taking anti-hypertensive medication or recorded BP \geq 140/90 (all measured within the past 2.5 years).

6. Defined as diabetes if self-reported diagnosis or fasting blood sugar \geq 7.0 (all measured within the past 2.5 years).

7. Defined as HIV positive if self-reported diagnosis or positive test result ever, and HIV negative if negative test result in past 4 years.

seeing at 4.2% (95% CI 3.9-4.6%) (*Extended Data: Table 1*). Prevalence of self-reported disability in any domain increased with age in both men and women, with 3.5% (95% CI 3.0-4.0%) of adults under age 35 reporting disability, compared to 56.2% (95% CI 50.4-61.8%) of those aged 80+, see [Table 2](#). 24.0% (95% CI 21.5-26.7%) of adults not working reported disability versus 8.0% (95% CI 7.4-8.5%) of working adults. [Figure 2](#) demonstrates a higher prevalence of self-reported disability in women than men in every age group, but with overlapping confidence intervals in all but the oldest age group. Assuming constant age- and sex- specific prevalence over time and applying these to the changing population structure between 2004 and 2016, [Figure 3](#) shows that the predicted crude prevalence of disability would have increased only slightly over time: from 9.3% to 9.6% for women and 7.0% to 7.2% for men. However, the number of people with disability would have increased around 1.5 times due to an ageing population and population growth.

We found that obesity and diabetes were associated with self-reported disability adjusted for age and sex, whereas hypertension and HIV were not ([Table 3](#)). The association between overweight and obesity and disability was apparent in women ($p=0.005$) and remained after adjusting for hypertension and diabetes. The same pattern was seen in men, but the numbers were smaller as obesity was uncommon among men and the association was not significant. Diabetes was associated with self-reported disability among men, but not women, with an OR of 2.47 (95%CI 1.32-4.64) adjusted for age, which remained after adjusting for BMI. The association between obesity and disability was driven by a strong association with difficulty walking (OR 2.78; 95% CI 1.94-3.98), and diabetes was associated with difficulty seeing (OR 2.28; 95% CI 1.39-3.73). Hypertension was also associated with difficulty walking, but overall was not associated with self-reported disability (*Extended Data: Table 2*). [Figure 4](#) shows that age-specific prevalence of self-reported disability

Table 2. Prevalence of disability in any domain by socio-demographic background, stratified by sex.

	Women		Men		Total	
	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)
Overall	731/7437	9.8 (9.2-10.5)	308/3426	9.0 (8.1-10.0)	1039/10863	9.6 (9.0-10.1)
Age group						
18-34	137/3817	3.6 (3.0-4.2)	48/1545	3.1 (2.3-4.1)	185/5362	3.5 (3.0-4.0)
35-44	90/1478	6.1 (5.0-7.4)	34/711	4.8 (3.4-6.6)	124/2189	5.7 (4.8-6.7)
45-54	100/814	12.3 (10.2-14.7)	39/443	8.8 (6.5-11.8)	139/1257	11.1 (9.4-12.9)
55-64	97/606	16.0 (13.3-19.1)	47/306	15.4 (11.7-19.8)	144/912	15.8 (13.6-18.3)
65-69	49/213	23.0 (17.8-29.1)	18/105	17.1 (11.1-25.6)	67/318	21.1 (16.9-25.9)
70-74	68/173	39.3 (32.3-46.8)	34/101	33.7 (25.1-43.4)	102/274	37.2 (31.7-43.1)
75-79	81/165	49.1 (41.5-56.7)	34/96	35.4 (26.5-45.5)	115/261	44.1 (38.2-50.1)
80+	109/171	63.7 (56.3-70.6)	54/119	45.4 (36.7-54.4)	163/290	56.2 (50.4-61.8)
Education						
None	99/296	33.4 (28.3-39)	19/69	27.5 (18.3-39.2)	118/365	32.3 (27.7-37.3)
Primary (part or completed)	541/4980	10.9 (10-11.8)	199/1833	10.9 (9.5-12.4)	740/6813	10.9 (10.1-11.6)
Secondary (part or completed)	70/1759	4.0 (3.2-5.0)	75/1265	5.9 (4.8-7.4)	145/3024	4.8 (4.1-5.6)
Tertiary	12/351	3.4 (2-5.9)	14/247	5.7 (3.4-9.3)	26/598	4.3 (3-6.3)
Occupation						
Not working	165/621	26.6 (23.2-30.2)	78/391	19.9 (16.3-24.2)	243/1012	24.0 (21.5-26.7)
Manual work	5/89	5.6 (2.4-12.8)	20/387	5.2 (3.4-7.9)	25/476	5.3 (3.6-7.7)
Farmer/ fisherman	491/5721	8.6 (7.9-9.3)	192/2327	8.3 (7.2-9.4)	683/8048	8.5 (7.9-9.1)
Non-manual work ¹	53/930	5.7 (4.4-7.4)	16/309	5.2 (3.2-8.3)	69/1239	5.6 (4.4-7.0)
Union						
Not in a union ²	410/2343	17.5 (16-19.1)	69/870	7.9 (6.3-9.9)	479/3213	14.9 (13.7-16.2)
In a union	321/5090	6.3 (5.7-7.0)	239/2553	9.4 (8.3-10.6)	560/7643	7.3 (6.8-7.9)

1. Including those working in trade and professionals

2. Including never married, divorced, and widowed

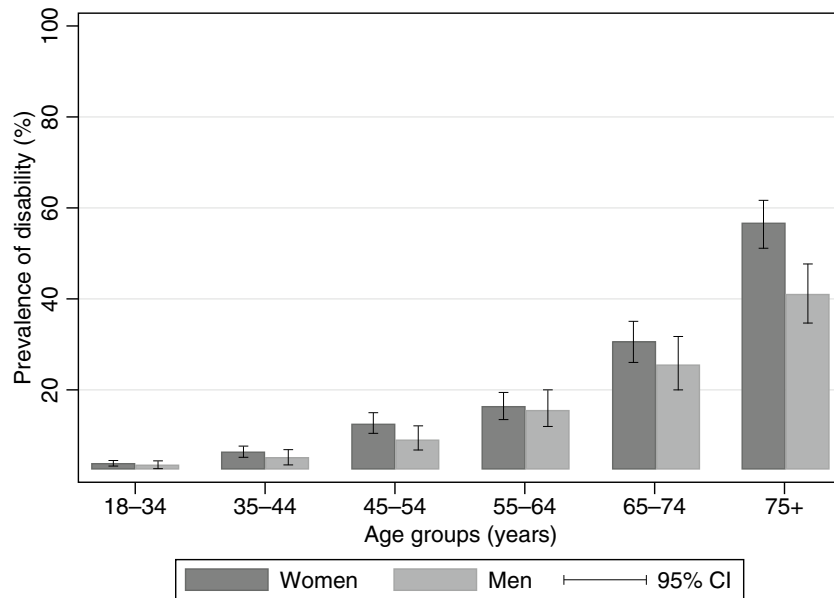


Figure 2. Age and sex specific prevalence of self-reported disability.

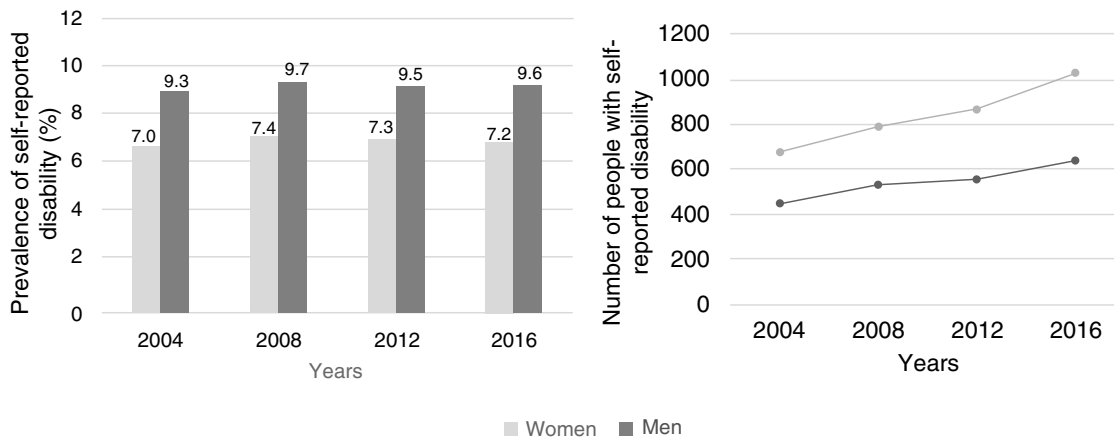


Figure 3. Simulated prevalence of self-reported disability over time since 2014. Simulated prevalence of self-reported disability and numbers of people reporting disability over time in 4-year intervals since 2014, by applying age- and sex-specific prevalence rates from the Round 1 census to the age and sex structure of the HDSS population.

appeared to be higher with obesity and diabetes than with hypertension, and lower with HIV-infection than any of the other conditions examined. However, the confidence intervals were overlapping.

Table 4 shows the concordance of self-reported disability in each disability domain over the two rounds. Of those who reported “no difficulty” or “can’t do at all” at Round 1, the majority stayed within the same category at Round 2. However, most people who reported “some difficulty” or “a lot of difficulty” changed category, usually with an improvement in functional

status (i.e. less disability). Of participants reporting “some difficulty” in any domain in Round 1, 44.5-80.3% reported “no difficulty” the following year in that domain; of those reporting “a lot of difficulty” in Round 1, 26.7-75.0% reported “no difficulty” the following year. Those aged under 60 were more likely to report an improved functional status at Round 2 compared to those aged over 60 (Extended Data: Table 3).

Discussion

Around one in ten study participants reported disability, most commonly difficulty walking or seeing. Prevalence was higher

Table 3. Logistic regression analysis of the association between obesity, hypertension, diabetes, and HIV with self-reported disability.

		Model 1*			Model 2**			Model 3***		
		Number reporting difficulty ¹	OR (95% CI)	p-value	Number reporting difficulty	OR (95% CI)	p-value	Number reporting difficulty	OR (95% CI)	p-value
BMI (kg/m²)										
Women	<18.5 kg/m ²	51/481	0.68 (0.48-0.95)		32/326	0.66 (0.43-1.01)				
	18.5-24.9 kg/m ²	357/4335	1	0.005	263/3227	1	0.005			
	25-29.9 kg/m ²	152/1401	1.20(0.97-1.49)		124/1075	1.28 (1.00-1.63)				
Men	30+ kg/m ²	79/519	1.30 (0.98-1.72)		66/427	1.39 (1.01-1.92)				
	<18.5 kg/m ²	41/298	1.15 (0.78-1.70)		28/196	1.20 (0.75-1.93)				
	18.5-24.9 kg/m ²	184/2363	1	0.09	137/1688	1	0.16			
	25-29.9 kg/m ²	37/266	1.36 (0.91-2.03)		30/192	1.21 (0.75-1.96)				
	30+ kg/m ²	9/35	2.62 (1.14-6.04)		9/28	2.93 (1.15-7.46)				
Hypertension										
Women	No hypertension	366/4874	1	0.18				362/4862	1	0.40
	Hypertension	215/837	1.03 (0.82-1.30)					203/823	0.90 (0.71-1.15)	
Men	No hypertension	144/2026	1	0.13				139/2019	1	0.28
	Hypertension	90/434	1.30 (0.93-1.81)					89/432	1.21 (0.86-1.71)	
Diabetes										
Women	No diabetes	478/4990	1	0.37				466/4971	1	0.09
	Diabetes	20/87	1.29 (0.74-2.24)					19/86	1.11 (0.63-1.97)	
Men	No diabetes	190/2057	1	0.007				186/2051	1	0.003
	Diabetes	18/53	2.47 (1.32-4.64)					18/53	2.37 (1.25-4.52)	
HIV										
Women	HIV negative	454/5134	1	0.32						
	HIV positive	56/719	0.86 (0.64-1.16)							
Men	HIV negative	454/5134	1	0.32						
	HIV positive	56/719	0.86 (0.64-1.16)							

*Model 1: Adjusted for age (as linear variable)

**Model 2: Adjusted for age (as a linear variable), hypertension, and diabetes

***Model 3: Adjusted for age (as a linear variable) and BMI

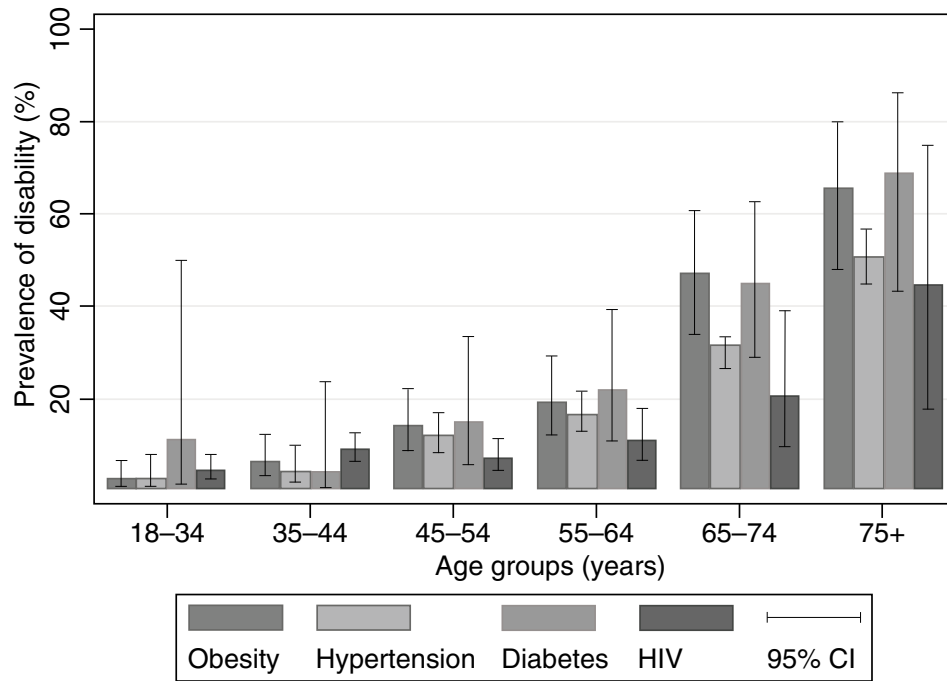


Figure 4. Age-specific prevalence of self-reported disability with obesity, hypertension, diabetes, and HIV-infection.

Table 4. Consistency of reporting of self-reported disability over time.

	Round 1	No difficulty	Some difficulty	A lot of difficulty	Can't do at all
Difficulty seeing		n % (95% CI)	n % (95% CI)	n % (95% CI)	n % (95% CI)
	No difficulty	5719/6282 91.0% (90.3-91.7%)	519/6282 8.3% (7.6-9.0)	44/6282 0.7% (0.5-0.9%)	0/6282 0%
	Some difficulty	730/1639 44.5% (42.2-47.0%)	816/1639 49.9% (47.4-52.2%)	91/1639 5.6% (4.5-6.8%)	2/1639 0.1% (0.03-0.5%)
	A lot of difficulty	98/367 26.7% (22.4-31.5%)	205/367 55.9% (50.7-60.9%)	52/367 14.2% (11.0-18.1%)	12/367 3.3% (1.9-5.7%)
	Can't do at all	0/21 0%	2/21 9.5% (2.4-31.1%)	2/21 9.5% (2.4-31.1%)	17/21 81.0% (58.8-92.7%)
Difficulty hearing	No difficulty	7644/7848 97.4% (97.0-97.7%)	189/7848 2.4% (2.1-2.8%)	14/7848 0.2% (0.1-0.3%)	1/7848 0.01% (0-0.09%)
	Some difficulty	229/385 59.5% (54.5-64.3%)	134/385 34.8% (30.2-39.7%)	20/385 5.2% (3.4-7.9%)	2/385 0.52% (0.1-2.1%)
	A lot of difficulty	19/66 28.8% (19.2-40.8%)	29/66 43.9% (32.5-56.0%)	16/66 24.2% (15.4-36.0%)	2/66 3.0% (0.8-11.3%)
	Can't do at all	0/9 0%	0/9 0%	3/9 33.3% (11.1-66.7%)	6/9 66.7% (33.3-88.9%)

	Round 1	No difficulty	Some difficulty	A lot of difficulty	Can't do at all
Difficulty walking	No difficulty	6276/6771 92.7% (92.0-93.3%)	434/6771 6.4% (5.9-7.0%)	57/6771 0.8% (0.7-1.1%)	4/6771 0.06% (0.02-0.2%)
	Some difficulty	618/1141 54.2% (51.3-57.0%)	403/1141 35.3% (32.6-38.1%)	118/1141 10.3% (8.7-12.3%)	2/1141 0.2% (0.04-0.7%)
	A lot of difficulty	126/373 33.8% (29.2-38.7%)	151/373 40.5% (35.6-45.6%)	92/373 24.7% (20.6-29.3%)	4/373 1.1% (0.4-2.8%)
	Can't do at all	2/22 9.1% (2.3-30.0%)	0/22 0%	6/22 27.3% (12.8-48.9%)	14/22 63.6% (42.3-80.7%)
Difficulty remembering	No difficulty	6011/6631 90.7% (89.9-91.3%)	564/6631 8.5% (7.9-9.2%)	55/6631 0.8% (0.6-1.1%)	1/6631 0.02% (0-0.1%)
	Some difficulty	1083/1478 73.3% (71.0-75.5%)	342/1478 23.1% (21.1-25.4%)	52/1478 3.5% (2.7-4.6%)	1/1478 0.07% (0.01-0.5%)
	A lot of difficulty	108/180 60.0% (52.7-66.9)	56/180 31.1% (24.8-38.2%)	13/180 7.2% (4.2-12.0%)	3/180 1.7% (0.5-5.0%)
	Can't do at all	0/1 0%	0/1 0%	1/1 100%	0/1 0%
Difficulty communication	No difficulty	8086/8184 98.8% (98.5-99.0%)	81/8184 1.0% (0.8-1.2%)	12/8184 0.2% (0.08-0.3%)	5/8184 0.06% (0.03-0.2%)
	Some difficulty	62/80 77.5% (67.1-85.3%)	13/80 16.3% (9.7-26.0%)	5/80 6.3% (2.6-14.2%)	0/80 0%
	A lot of difficulty	9/16 56.3% (32.4-77.5%)	3/16 18.8% (6.2-44.8%)	2/16 12.5% (3.1-38.6%)	2/16 12.5% (3.1-38.6%)
	Can't do at all	1/5 20.0% (2.7-69.1%)	0/5 0%	1/5 20.0% (2.7-69.1%)	3/5 60.0% (20.0-90.0%)
Difficulty with self-care	No difficulty	7434/7759 95.8% (95.3-96.2%)	273/7759 3.5% (3.1-4.0%)	46/7759 0.6% (0.4-0.8%)	6/7759 0.08% (0.03-0.2%)
	Some difficulty	301/375 80.3% (75.9-84.0%)	58/375 15.5% (12.2-19.5%)	13/375 3.5% (2.0-5.9%)	3/375 0.8% (0.3-2.5%)
	A lot of difficulty	111/148 75.0% (67.4-81.3%)	24/148 16.2% (11.1-23.1%)	12/148 8.1% (4.7-13.7%)	1/148 0.7% (0.1-4.6%)
	Can't do at all	2/11 18.2% (4.6-50.7%)	2/11 18.2% (4.6-50.7%)	5/11 45.5% (20.3-73.2%)	2/11 18.2% (4.6-50.7%)

Legend: Self-reported disability status of participants at Round 2, according to their status at Round 1, for all disability domains

in women than men and increased rapidly with age, with one in four adults over 50 reporting disability. While obesity and diabetes were associated with self-reported disability, hypertension and HIV were not. Reporting severe levels of disability (“can’t do at all”) in a functional domain was relatively consistent between the two rounds, whereas most of those who reported “some difficulty” or “a lot of difficulty” at Round 1 reported a changed disability category at Round 2, one year later.

Direct comparison of prevalence with other studies is challenging, even when the WG questions have been used, as population age distribution has a strong impact on prevalence and varies between sites, and age-specific prevalence is not usually presented. However, the simulation of (self-reported) disability in this site since 2004 suggests that the absolute number of people experiencing disability may have increased 1.5 times in only 12 years as the population grows and ages. In Malawi,

while only 3% of the country's population is aged over 65 currently, 67% of people are now surviving to age 65¹⁰, which is likely to further increase the prevalence of disability.

The discourse on disability in low and middle income countries (LMIC) links disability closely with poverty^{11–13}. Therefore, in Malawi, a poor and food-insecure country¹⁴, disability might be expected to be associated with under-nutrition and low BMI. However, our findings demonstrated a stepwise increase in odds of self-reported disability with increasing BMI, particularly among women, independent of hypertension and diabetes. This association was mainly driven by difficulty walking, which may suggest that obesity is a consequence of lack of exercise secondary to disability, or that obesity has led to disabling complications such as osteoarthritis¹⁵. Obesity is well-recognised to be associated with disability in high income countries (HIC)^{16–18}, but this association has only rarely been seen in LMIC^{19,20}. Similarly, while disability is strongly associated with diabetes in HIC^{21–23}, evidence in LMIC has been less consistent^{24–26}. Difficulty seeing in diabetes is likely to be secondary to diabetic eye disease, and perhaps in this rural Malawian setting, where diabetes is frequently undiagnosed and sub-optimally controlled²⁷, eye disease develops early in the disease course²⁸. Both obesity and diabetes are highly prevalent²⁷, and should be recognised as potentially important drivers for disability among this population.

Our finding that hypertension was not associated with self-reported disability was in keeping with a meta-analysis analysing the contribution of chronic diseases to disability in older people in LMIC²⁶. The literature on HIV infection and disability in sub-Saharan Africa is mixed: HIV has been shown to be associated with frailty^{29,30}, a syndrome closely linked to disability³¹, and a systematic review found that in 27 of 37 studies, people living with HIV had lower levels of functioning than those without HIV³². However, the data did not allow disaggregation by use of anti-retroviral therapy, and the association between HIV and disability may have changed over time as antiretroviral availability has improved³³.

No studies from LMICs have previously reported on consistency in disability categorisation over time. Our study found that most people who reported “can't do at all” for any domain at Round 1 consistently reported disability at Round 2. However, there was considerable movement between those reporting “some difficulty” and “a lot of difficulty” with many participants reporting an improved functional status, and less disability, the following year. This is likely to represent both an element of true fluctuation of disability and changing descriptions of a constant level of disability over time.

Our study has some important strengths. Due to the large sample size and collection of other chronic condition data, we can obtain precise estimates of self-reported disability prevalence and examine associations between health and disability. Collecting data on disability and chronic conditions at different contacts reduces the likelihood of spurious self-report or observer bias. As further rounds of census data are collected, we will be able to analyse trends over time and further

understanding about the trajectories of disability prevalence in this context.

There are some inherent limitations to self-report of disability, particularly in certain domains. People with difficulty hearing or communicating may have challenges interacting with the interviewer, and people with difficulty remembering may lack insight into their difficulties. However, self-report does allow a reflection of an individual's lived experiences of disability more than objective measures of impairment or observations of function. Comparisons of self-reported disability between age-groups, sexes, and externally to other populations may be less valid than when using objective measures of disability as there may be cultural differences between willingness to report disability or different levels of stoicism (or expected function)^{34,35}. Furthermore, the WG questions do not capture a complete picture of disability, as they do not include pain or low mood and focus more on functional limitations than participation. However, their brevity does allow the questions to be easily added to existing surveys. The WG recommends defining disability as at least “a lot of difficulty”. However, if participants' descriptions of constant disabilities do vary over time between “some difficulty” (categorised as no disability) and “a lot of difficulty” (categorised as having disability), using this cut-off may lead to measurement error and imprecision in estimates of associations and trends.

Our missing data for those absent from home at the time of survey, particularly younger men, may have led to an over-estimate of disability prevalence, as this group is likely to have a lower disability prevalence than those at home. Conversely, some people with disability may have been excluded from the survey, for example if they were hidden, in residential care, or away seeking healthcare. We are also missing data on HIV status, hypertension, and diabetes for substantial numbers of participants, and for HIV, we were more likely to capture positive than negative diagnoses as data was partly gathered from participants attending HIV clinics⁸. This may have introduced some bias into our analysis of the association between chronic disease and disability.

Conclusion

Self-reported disability prevalence in rural Malawi is around 10% in adults and the number of people experiencing disability is increasing. Notably, even in this very poor rural setting there are significant independent associations between both obesity and diabetes self-reported disability, both of which are already a considerable burden in this population. Combined with an ageing and expanding population the number of people living with disability is likely to increase significantly over the coming years. Further investigation into the needs of this potentially vulnerable population is vital in order to create inclusive public health and social policies.

Data availability

Underlying data

LSHTM Data Compass: Malawi Epidemiology and Intervention Research Unit Non-Communicable Disease Survey data, 2013–2017. <https://doi.org/10.17037/DATA.00000961>³⁶. Data are available under the terms of the [Creative Commons Attribution 3.0 International license](https://creativecommons.org/licenses/by/3.0/) (CC-BY 3.0).

Summary demographic datasets are publicly available through the [INDEPTH iShare platform](#).

Longitudinal data (demographic surveillance episodes and linked rounds of disability questionnaires) cannot be sufficiently de-identified for public availability. Application may be made for access through the MEIRU director (mia.crampin@lshtm.ac.uk) or data scientist Chifundo Kanjala (chifundo.kanjala@lshtm.ac.uk). Those wishing to access the data will need to provide a brief proposal for what the data will be used for as a condition of access.

Extended data

Harvard Dataverse: Self-reported disability in rural Malawi: prevalence, incidence, and relationship to chronic disease: Extended Data. <https://doi.org/10.7910/DVN/IAELBG37>.

This project contains the following extended data:

1. Extended Data Table 1: Prevalence (%) of self-reported disability in each disability domain by age at Round 1

2. Extended Data Table 2: Logistic regression analysis of the association between BMI, hypertension, diabetes, and HIV with self-reported disability in different domains at Round 1
3. Extended Data Table 3: Self-reported disability status at Round 2, according to their status at Round 1, for all disability domains stratified by age group

Data are available under the terms of the [Creative Commons Zero “No rights reserved” data waiver](#) (CC0 1.0 Public domain dedication).

Grant information

This work was supported by the Wellcome Trust [098610], which supported both the HDSS census rounds and NCD survey.

The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

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Open Peer Review

Current Peer Review Status:  

Version 1

Reviewer Report 08 August 2019

<https://doi.org/10.21956/wellcomeopenres.16579.r36026>

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Thank you for the opportunity to review this manuscript. I have read the paper with high interest and have comments for the authors to consider in revising their manuscript.

The work is not clearly and accurately presented. It is not easy to understand what messages the authors want to deliver. There are quite a lot of analysis results presented in the paper, without relevant rationale. The thread between different parts of the paper is missing.

The objectives are not well-phrased, and different concepts seem to be misused.

- Did the authors want to measure the prevalence or incidence of disability? Or both? The term "incidence" only appears in the title and objective of the paper, but nowhere else. With the follow-up data in the HDSS setting, the authors should be able to estimate the incidence of disability among the study population. The use of panel data would strengthen the quality of the paper.
- What is the rationale of assessing "consistency" disability reported in two rounds of population census? In research, the term "consistency" is closely related to "reliability". A measure is considered to be reliable if it yields similar results under similar/consistent conditions. The physical, mental and social conditions at different time points can influence the self-reported disability measured 1-2 years apart. Therefore, the two measurements were not done under consistent conditions. Any changes observed in the self-reported disability measured 1-2 years apart could, therefore, reflect real changes in the health conditions, not merely consistency in reporting the disability.
- What is the rationale of including "overweight and obesity" as a chronic disease?
- Though the authors had access to two rounds of panel data on disability (round 1 in 2014-2015 and round 2 in 2015-2016), this study was designed as a cross-sectional study. The study combined population-based data (NCD survey in 2013-2015, HIV serosurvey in

2011) or hospital data (HIV data from ART clinics) collected on different occasions. There is a serious threat of selection bias due to non-participation in surveys and possibly data missing not in random, which could yield invalid estimates reported in this paper.

- How could the authors ensure that data from different studies were collected using the same protocols? In other words, are the data comparable and is there no threat of misclassification bias? For example, the authors wrote, "Body mass index (BMI) was also taken from the NCD survey unless data on height and weight was available from other studies in the same population obtained closer to the date of the Round 1 census". The authors should be transparent and declare what those other studies are.
- Though the authors did not attempt to ascertain causality, it is still important to ensure that all the exposure variables were measured before the measurement of disability. Some of the exposure data might be collected after the measurement of disability.
- As not all the study sample who had disability data in Round 1 ($n=10863$) participated in the other surveys, information about their BMI, hypertension, diabetes, and HIV status (as shown in Table 1) were therefore missing. Only individuals who had complete information on the exposures and outcome (disability) will be included in the regression analysis when all these variables are included in the model (as shown in Model 1 in Table 3). It is unclear how many these individuals were, as Model 1 might not be valid if it might be based on a small number of individuals.
- As there are significant amounts of missing data in the dataset, the authors should consider doing multiple imputation. But before coming to this decision, please consider the appropriateness to link data from different sources as discussed above.
- I do not see the reason to estimate the simulated prevalence of self-reported disability by direct standardisation of the age- and sex-specific disability prevalence in 2014 to the population structure the previous ten years. By doing this, the authors assume that all other factors affecting disability were constant over time. This assumption is invalid. Our previous study on disability in low-and-middle-income countries shows the different factors affecting disability in different countries¹.
- As the age and sex of the respondents who were successfully recruited into Round 1 differ significantly (see 1st paragraph in the Results section), it is important for the authors to weigh all the analyses to get a valid estimate of disability in the population. Otherwise, I suspect that the prevalence of self-reported disability in this study is over-estimated. This is mainly due to the larger number of older population and women who participated in the study.

The following are additional issues that the author should address to improve the clarity of the text.

- The authors need to give more details on how the composite score of socioeconomic status was calculated. What statistical method was used to do the analysis?
- It is surprising to see that there are significant missing data in the socioeconomic variables collected in an HDSS setting. One would expect to see reasonably good quality household-level data from a well-functioning HDSS.

- Table 1 and 2: The total columns are not needed. As there are many differences between sexes, it is more appropriate to present sex-stratified analyses.
- Table 3 needs to be revised to make it more comprehensible. Please indicate if Model 1 is a multivariable model, and not bivariate models of all the variables. If hypertension and diabetes were included in the analysis in Model 2, why weren't their results presented in the table? Same question for BMI in Model 3.
- Table 4. 9.1% respondents could not walk at all in the baseline and reported no difficulty in the follow-up. How could this be explained considering the research setting?

In brief, I would suggest the authors reformulate the objectives of this study, assess what data sources could be used to address the research questions (considering the limitation of linking the different datasets), weight all the analyses and conduct multiple imputation in order to get valid estimates to be reported in this study.

I hope my comments are not too harsh. I wish the authors all the best in revising the work.

References

1. Lestari S, Ng N, Kowal P, Santosa A: Diversity in the Factors Associated with ADL-Related Disability among Older People in Six Middle-Income Countries: A Cross-Country Comparison. *International Journal of Environmental Research and Public Health*. 2019; **16** (8). [Publisher Full Text](#)

Is the work clearly and accurately presented and does it cite the current literature?

Partly

Is the study design appropriate and is the work technically sound?

Partly

Are sufficient details of methods and analysis provided to allow replication by others?

No

If applicable, is the statistical analysis and its interpretation appropriate?

No

Are all the source data underlying the results available to ensure full reproducibility?

No

Are the conclusions drawn adequately supported by the results?

Partly

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Ageing and disability, risk factor surveillance, epidemiology analysis, longitudinal data analysis.

I confirm that I have read this submission and believe that I have an appropriate level of

expertise to state that I do not consider it to be of an acceptable scientific standard, for reasons outlined above.

Author Response 18 Nov 2019

Josephine Prynn, Malawi Epidemiology and Intervention Research Unit (MEIRU), Lilongwe, Malawi

Dear Professor Ng,

Many thanks for your considered comments. We have made some major changes to the submission based on these and believe we have improved its quality. We have clarified our findings on incidence of disability, dropped the simulation of disability prevalence over time, and reviewed the way we were considering the panel data and changes in responses between the two rounds. We hope that you will find that this updated version meets your approval.

Detailed responses to your comments below:

Did the authors want to measure the prevalence or incidence of disability? Or both? The term "incidence" only appears in the title and objective of the paper, but nowhere else. With the follow-up data in the HDSS setting, the authors should be able to estimate the incidence of disability among the study population. The use of panel data would strengthen the quality of the paper.

Response: We have updated Table 4 to include disability incidence over the year between the two rounds.

What is the rationale of assessing "consistency" disability reported in two rounds of population census? In research, the term "consistency" is closely related to "reliability". A measure is considered to be reliable if it yields similar results under similar/consistent conditions. The physical, mental and social conditions at different time points can influence the self-reported disability measured 1-2 years apart. Therefore, the two measurements were not done under consistent conditions. Any changes observed in the self-reported disability measured 1-2 years apart could, therefore, reflect real changes in the health conditions, not merely consistency in reporting the disability.

Response: Thank you for this point. We have changed the wording from consistency to simply describing changes between the two rounds. We discuss how these changes may represent real changes in health conditions, or differences in reporting over time.

What is the rationale of including "overweight and obesity" as a chronic disease?

Response: Obesity and overweight are well-recognised risk factors for multiple health conditions and as such was of interest to us. We have changed the wording from chronic diseases to chronic conditions however, as we recognise that obesity itself may not be considered a disease.

Though the authors had access to two rounds of panel data on disability (round 1 in 2014-2015 and round 2 in 2015-2016), this study was designed as a cross-sectional study. The

study combined population-based data (NCD survey in 2013-2015, HIV serosurvey in 2011) or hospital data (HIV data from ART clinics) collected on different occasions. There is a serious threat of selection bias due to non-participation in surveys and possibly data missing not in random, which could yield invalid estimates reported in this paper.

Response: Use of all available data sources on HIV was important to minimise the amount of missing HIV data. We have acknowledged the risk of bias from missing data on the different health states and have now added a description of the pattern of missing data into the results to further inform the reader.

How could the authors ensure that data from different studies were collected using the same protocols? In other words, are the data comparable and is there no threat of misclassification bias? For example, the authors wrote, "Body mass index (BMI) was also taken from the NCD survey unless data on height and weight was available from other studies in the same population obtained closer to the date of the Round 1 census". The authors should be transparent and declare what those other studies are.

Response: We have clarified that only 0.8% of BMI data came from studies other than the NCD survey or the census. The NCD survey, the census, and all of the other 9 studies were performed by the Malawi Epidemiology and Intervention Research Unit using an identical protocol, and in many cases the same members of staff were performing the measurements.

Though the authors did not attempt to ascertain causality, it is still important to ensure that all the exposure variables were measured before the measurement of disability. Some of the exposure data might be collected after the measurement of disability. Some of the BMI data was collected after the measurement of disability.

Response: A sensitivity analysis has been added excluding any BMI data collected after the measurement of disability.

As not all the study sample who had disability data in Round 1 (n=10863) participated in the other surveys, information about their BMI, hypertension, diabetes, and HIV status (as shown in Table 1) were therefore missing. Only individuals who had complete information on the exposures and outcome (disability) will be included in the regression analysis when all these variables are included in the model (as shown in Model 1 in Table 3). It is unclear how many these individuals were, as Model 1 might not be valid if it might be based on a small number of individuals. As there are significant amounts of missing data in the dataset, the authors should consider doing multiple imputation. But before coming to this decision, please consider the appropriateness to link data from different sources as discussed above.

Response: To reduce the amount of data excluded from the regression models, we have now included an "unknown" category when the variable is a covariate rather than the exposure of interest.

I do not see the reason to estimate the simulated prevalence of self-reported disability by direct standardisation of the age- and sex-specific disability prevalence in 2014 to the population structure the previous ten years. By doing this, the authors assume that all other factors affecting disability were constant over time. This assumption is invalid. Our previous study on disability in low-and-middle-income countries shows the different factors affecting

disability in different countries¹.

Response: We have removed this analysis from the paper.

As the age and sex of the respondents who were successfully recruited into Round 1 differ significantly (see 1st paragraph in the Results section), it is important for the authors to weigh all the analyses to get a valid estimate of disability in the population. Otherwise, I suspect that the prevalence of self-reported disability in this study is over-estimated. This is mainly due to the larger number of older population and women who participated in the study.

Response: We now also include age-specific prevalence weighted to the age-population of the underlying census population.

The following are additional issues that the author should address to improve the clarity of the text.

The authors need to give more details on how the composite score of socioeconomic status was calculated. What statistical method was used to do the analysis?

Response: Thank you for this comment and apologies for the lack of clarity. In fact, we didn't use a composite score of socio-economic status – we have updated the text in the Methods section to clarify that. A household possession score was used in the analysis and considered as a potential confounder, but not included in any of the tables nor the final analysis, so we do not currently provide detailed information on how it was calculated. The variables occupation and education can be considered as proxies for SES.

It is surprising to see that there are significant missing data in the socioeconomic variables collected in an HDSS setting. One would expect to see reasonably good quality household-level data from a well-functioning HDSS.

Response: Household possession score data was gathered from the NCD survey rather than the HDSS census and had some missing data. The other proxies we considered for socio-economic status were “mobile phone use” and “education”, neither of which had considerable missing data. We have changed the text in the Methods section to clarify that.

Table 1 and 2: The total columns are not needed. As there are many differences between sexes, it is more appropriate to present sex-stratified analyses.

Response: We have updated the tables to remove the totals columns and present sex-stratified columns.

Table 3 needs to be revised to make it more comprehensible. Please indicate if Model 1 is a multivariable model, and not bivariate models of all the variables. If hypertension and diabetes were included in the analysis in Model 2, why weren't their results presented in the table? Same question for BMI in Model 3.

Response: The text of the Statistical Analysis section of the Methods and the headings and footnotes of the tables have been updated to clarify this. Model 1 is a bivariate model; hypertension and diabetes were included in Model 2, but the exposure of interest in that model is BMI.

Table 4. 9.1% respondents could not walk at all in the baseline and reported no difficulty in the follow-up. How could this be explained considering the research setting?

Response: The percentage of 9.1% you mention represents small numbers (2/22) and has wide confidence intervals. It may represent participants with acute illness that had resolved in the intervening time, or impairments that were successfully treated. This has been added to the Discussion section.

In brief, I would suggest the authors reformulate the objectives of this study, assess what data sources could be used to address the research questions (considering the limitation of linking the different datasets), weight all the analyses and conduct multiple imputation in order to get valid estimates to be reported in this study.

Response: Many thanks for these comments, which have undoubtedly led to an improved quality of this submission. As outlined above, we have changed the objectives of the study to remove the simulation of disability prevalence over time, and better address the question of incidence of disability. We have updated the interpretation of the panel data as you suggested, weighted our prevalence estimates to the underlying census population, and added more detail and sensitivity analyses to address the issue of missing data.

Many thanks again for your time and your valuable comments.

Competing Interests: None

Reviewer Report 22 July 2019

<https://doi.org/10.21956/wellcomeopenres.16579.r35881>

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Sophie Mitra

Fordham University, New York, NY, USA

The paper deals with a very important and yet neglected topic: disability prevalence and its correlates in a resource poor setting. It is very well written and the analysis is carefully executed. I think the biggest contribution of this paper is to study the prevalence of functional limitations and the health conditions associated with functional limitations in a low-income setting.

I have several major comments that need to be addressed for the paper to become indexed.

1. Methods

- Definition of the category of disability should be expanded to include 'some difficulty' at least in a sensitivity analysis.
- The authors strictly follow the recommendations of the WG that focus on only two

categories (a lot of difficulty and unable to do) but there is work to figure out how disability analyses change as this definition is expanded to include 'some difficulty'.

- In addition, the authors find that “most people who reported 'some difficulty' or 'a lot of difficulty' changed category, usually with an improvement in functional”. This is a very important result. In addition, in the discussion, the authors note: “over time between “some difficulty” (categorised as no disability) and “a lot of difficulty” (categorized as having disability), using this cut-off may lead to measurement error and imprecision in estimates of associations and trends.”
- Recently, one study (Mitra 2018¹) also studied people reporting some difficulty under disability, although this is not strictly in line with the recommendations of the WG that focus on only two categories (a lot of difficulty and unable to do) as done in this study. Given the results above and given similar results in Mitra (2018)¹ using panel data on disability for Ethiopia and Uganda using two waves of data, we recommend that the authors include the additional category 'some difficulty' in their analysis (or at least in a sensitivity analysis) and mention results of disability prevalence and correlates when the group with some difficulty is included. This affects results in Tables 2 and 3 and Fig 4.
- Figure 3: I do not understand the point of doing the simulation. This should be dropped (or at the very least motivated convincingly).

2. Motivation, Contribution of the study and review of the literature.

- The authors should motivate the analysis in light of recent related calls for research on disability and development (UN 2018², Groce and Mont 2018³, Mitra 2018b⁴).
- The authors need to think more carefully about the contribution of their study in light of a thorough review of the literature on disability in low-income settings. I think that the main contribution of this paper is to study the prevalence of functional limitations and the health conditions associated with functional limitations in a low income setting. To my knowledge, the association with health conditions using biomarkers as done in this study (except for HIV) has not been done before.
- In contrast, the exploitation of longitudinal data on functional limitations has been done before. Under Discussion, the authors write “No studies from LMICs have previously reported on consistency in disability categorisation over time.” Please note that Mitra (2018a)¹ does that for two countries in Africa, so the statement should be qualified. To my knowledge, this is true for Malawi.
- The authors should also compare their results with those on Malawi in Mitra (2018a)¹.

3. A number of edits are required throughout the paper to improve clarity. Some are noted below.

- Abstract/conclusion: “Further research into the needs of this population is crucial”: I suggest replacing “needs” with “situation”.
- Introduction: “The prevailing framework for conceptualising disability is using the World Health Organization (WHO) International Classification of Functioning and Disease¹.” Instead of “prevailing” I recommend, “commonly used”. Instead of “or more holistically on participation and disability”, I recommend “or more

holistically on participation and activities”.

Also, the authors should note if they use ‘disability’ as an umbrella term for impairments, activity limitations and participation restrictions as in the ICF. It sounds like they do in the introduction. However, later, they use the term as per the Washington Group measure referring to a lot of difficulty or unable to do difficulty in at least one of six domains. If they use it as an umbrella term (which is consistent with the ICF, their conceptual framework), then it would be more precise to simply refer to functional/activity limitations for their empirical results using the WG questions on functional/activity limitations.

- Methods: Please indicate if the six questions of the Washington Group were preceded by an introduction sentence clarifying that the questions are about difficulties related to health. The term “self reported difficulty” is used several times. I think this is unnecessary. It is enough to indicate once under Methods that functional difficulties are self-reported.
- Discussion: The term ‘objective’ to discuss disability measurement may not be clear to all readers: please use something else or clarify. You may want to use ‘clinical assessment”. The term ‘incidence’ is mentioned in the title only. Consider removing or use it (after defining it) in the analysis.

References

1. Mitra S: Disability, Health and Human Development. *SSRN Electronic Journal*. 2018. [Publisher Full Text](#)
2. United Nations: UN Flagship Report on Disability and Development 2018. [Accessed 22nd July 2019]. 2018. [Reference Source](#)
3. Groce N, Mont D: Counting disability: emerging consensus on the Washington Group questionnaire. *The Lancet Global Health*. 2017; **5** (7): e649-e650 [Publisher Full Text](#)
4. Mitra S: From Disability in Resource-Poor Settings to Policy and Research Opportunities in Global Health. *Am J Public Health*. 2018; **108** (9): 1163-1165 [PubMed Abstract](#) | [Publisher Full Text](#)

Is the work clearly and accurately presented and does it cite the current literature?

Yes

Is the study design appropriate and is the work technically sound?

Partly

Are sufficient details of methods and analysis provided to allow replication by others?

Partly

If applicable, is the statistical analysis and its interpretation appropriate?

Yes

Are all the source data underlying the results available to ensure full reproducibility?

Yes

Are the conclusions drawn adequately supported by the results?

Partly

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Disability; economics; public health

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Author Response 18 Nov 2019

Josephine Prynn, Malawi Epidemiology and Intervention Research Unit (MEIRU), Lilongwe, Malawi

Dear Professor Mitra,

Many thanks for your thoughtful comments on our paper. We appreciate the importance of thinking about “some difficulty” as well as “a lot of difficulty” when considering disability as defined by the Washington Group questions, and have updated our analyses accordingly. We have dropped the simulation of disability prevalence over time as you suggested, and we have been able to compare our results to those found using the other published literature that you brought to our attention.

Please find a detailed response to each of the issues raised below.

1. Methods

- Definition of the category of disability should be expanded to include ‘some difficulty’ at least in a sensitivity analysis.

Response: We have now included the prevalence of at least “some difficulty” into Table 2, and described the findings in the text.

- The authors strictly follow the recommendations of the WG that focus on only two categories (a lot of difficulty and unable to do) but there is work to figure out how disability analyses change as this definition is expanded to include ‘some difficulty’. In addition, the authors find that “most people who reported ‘some difficulty’ or ‘a lot of difficulty’ changed category, usually with an improvement in functional”. This is a very important result. In addition, in the discussion, the authors note: “over time between “some difficulty” (categorised as no disability) and “a lot of difficulty” (categorized as having disability), using this cut-off may lead to measurement error and imprecision in estimates of associations and trends.” Recently, one study (Mitra 2018¹) also studied people reporting some difficulty under disability, although this is not strictly in line with the recommendations of the WG that focus on only two categories (a lot of difficulty and unable to do) as done in this study. Given the results above and given similar results in Mitra (2018)¹ using panel data on disability for Ethiopia and Uganda using two waves of data, we recommend that the authors include the additional category ‘some difficulty’ in their analysis (or at least in a sensitivity analysis) and mention results of disability prevalence and correlates when the group with some difficulty is included. This affects results in Tables 2 and 3 and Fig 4.

Response: We have added a sensitivity analysis using at least “some difficulty” as an

outcome, available in the Extended Data.

- Figure 3: I do not understand the point of doing the simulation. This should be dropped (or at the very least motivated convincingly).

Response: We have dropped this.

2. Motivation, Contribution of the study and review of the literature.

- The authors should motivate the analysis in light of recent related calls for research on disability and development (UN 20182, Groce and Mont 20183, Mitra 2018b4).

Response: We have strengthened our motivation in the Introduction.

- The authors need to think more carefully about the contribution of their study in light of a thorough review of the literature on disability in low-income settings. I think that the main contribution of this paper is to study the prevalence of functional limitations and the health conditions associated with functional limitations in a low income setting. To my knowledge, the association with health conditions using biomarkers as done in this study (except for HIV) has not been done before.

Response: We have changed the wording in the Discussion and Conclusion to highlight this.

- In contrast, the exploitation of longitudinal data on functional limitations has been done before. Under Discussion, the authors write “No studies from LMICs have previously reported on consistency in disability categorisation over time.” Please note that Mitra (2018a)¹ does that for two countries in Africa, so the statement should be qualified. To my knowledge, this is true for Malawi.

Response: We have changed wording and now also compare results to those in Mitra 2018 for Ethiopia and Uganda.

- The authors should also compare their results with those on Malawi in Mitra (2018a)¹.

Response: This comparison is now included.

3. A number of edits are required throughout the paper to improve clarity. Some are noted below.

- Abstract/conclusion: “Further research into the needs of this population is crucial”: I suggest replacing “needs” with “situation”.

Response: Done.

- Introduction: “The prevailing framework for conceptualising disability is using the World Health Organization (WHO) International Classification of Functioning and Disease¹.” Instead of “prevailing” I recommend, “commonly used”.

Response: Done.

- Instead of “or more holistically on participation and disability”, I recommend “or more holistically on participation and activities”.

Response: Done.

- Also, the authors should note if they use ‘disability’ as an umbrella term for impairments, activity limitations and participation restrictions as in the ICF. It sounds like they do in the introduction. However, later, they use the term as per the Washington Group measure referring to a lot of difficulty or unable to do difficulty in at least one of six domains. If they use it as an umbrella term (which is consistent with the ICF, their conceptual framework), then it would be more precise to simply refer to functional/activity limitations for their empirical results using the WG questions on

functional/activity limitations.

Response: Thank you for your comment on this. Our use of the Washington Group questions meant that we were unable to assess participation restriction, which we acknowledge is a fundamental component of the ICF model of disability, and have added an acknowledgement and explanation of this in the Discussion.

- Methods: Please indicate if the six questions of the Washington Group were preceded by an introduction sentence clarifying that the questions are about difficulties related to health.

Response: The questions are asked within a section of questions related to health and fertility. We have added this information to the Methods section.

- The term “self reported difficulty” is used several times. I think this is unnecessary. It is enough to indicate once under Methods that functional difficulties are self-reported.

Response: Thanks for this comment – we have updated the prose accordingly.

- Discussion: The term ‘objective’ to discuss disability measurement may not be clear to all readers: please use something else or clarify. You may want to use ‘clinical assessment’.

Response: Done.

- The term ‘incidence’ is mentioned in the title only. Consider removing or use it (after defining it) in the analysis.

Response: We have now included incidence in Table 4 using the panel data from the 2 consecutive surveys.

Many thanks again for your time.

Competing Interests: None