









RESEARCH ARTICLE

REVISED **Self-reported disability in rural Malawi: prevalence, incidence, and relationship to chronic conditions [version 2; peer review: 1 approved with reservations, 1 not approved]**

Previously titled: Self-reported disability in rural Malawi: prevalence, incidence, and relationship to chronic disease

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	1	2
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version 2	report	report
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Any reports and responses or comments on the article can be found at the end of the article.

Keywords

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

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REVISED Amendments from Version 1

The main updates that we have made to our submission are as follows:

We have dropped the simulation of disability prevalence from our analysis.

We have considered disability as defined by participants reporting “some difficulty” as well as “a lot of difficulty” or “can’t do at all” in any domain.

Two columns have been removed from [Table 1](#) for clarity, [Table 2](#) has been expanded and clarified, [Table 3](#) has been edited for consistency in decimals and two extra columns depicting incident and resolution of disability have been added to [Table 4](#).

[Figure 2](#) has also been updated to depict age and sex specific prevalence of self-reported disability, defined as reporting at least “a lot of difficulty” in any domain, and [Figure 3](#) removed.

We have clarified our findings on incidence and resolution of disability between the two census rounds.

Any further responses from the reviewers can be found at the end of the article

Introduction

Disability is a complex and evolving concept. The commonly-used 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. There have been global calls for research on disability:^{5,6} The United Nations calls specifically for disability prevalence data using the ICF model, including through integration with national censuses and population surveys.

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 activities, 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 Statistics⁷, to improve data comparability⁸. 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 services⁹. 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 conditions in this cohort. Four markers of different health states 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 population¹⁰. The WG short set questions were added onto the census in 2014 for individuals aged 18 and over. During a section of questions related to health and fertility, participants are asked

the following six questions, translated into the local language of Chitumbuka:

- 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 elsewhere¹¹. 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.

Data on body mass index (BMI) was available from the census survey when disability data was collected. Where this was missing, BMI data was taken from the NCD survey or other studies in the same population obtained closer to the date of the Round 1 census. All these studies used the same procedures to measure height and weight: both are measured twice, and BMI is calculated from the mean of these measures. Of participants included in this study, 3597 (37.2%) of BMI variables came from the census survey, 5987 (62.0%) from the NCD survey, and 77 (0.8%) from other surveys. All BMI measures were taken within 3 years before or after the Round 1 census date.

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

We used two definitions of disability in this analysis: primarily we defined disability as participants reporting “a lot of difficulty” or “can't do at all” in at least one of the domains asked about, as recommended by the WG¹²; and additionally as participants reporting at least “some difficulty” in any domain. 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 and standardised this to the age population of the underlying census population.

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, so we excluded them from the final models. Overweight and obesity are known risk factors for hypertension and diabetes, and we considered that BMI might also be an independent risk factor for disability. Therefore, in Model 2, we control for hypertension and diabetes to examine the relationship between BMI and disability independent of its role as a risk factor for these diseases. In Model 3, we control for BMI when examining the relationships of each of hypertension and diabetes with disability, as it is a potential confounder.

As a sensitivity analysis, we ran a logistic regression model examining the relationship between BMI and disability excluding those with BMI measured after the census date. Secondly, we ran another model examining the relationship between BMI, hypertension, diabetes, and HIV using at least “some difficulty” as the disability outcome variable.

For those who also had disability data from Round 2, we examined the proportion whose disability status had changed between the two rounds, and calculated the incidence of disability between the two rounds (i.e. moved from no difficulty/some difficulty to a lot of difficulty/can't do at all, and the proportion who had resolution of disability between the two rounds (i.e. moved from a lot of difficulty/can't do at all to no difficulty/some difficulty). 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 disability; of those who did not, 28 were seen but missing data on disability status, and the remainder were not at home. Of those with data on disability status, 711 (6.6%) were provided by a proxy. 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](#). There was considerable missing data on hypertension, diabetes, and HIV status. More data was missing on these health states in men than women, and among those who were not working

than any other occupation group. More older people were missing data on HIV status, whereas more younger people were missing data on hypertension and diabetes. 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 crude prevalence of disability (at least “a lot of difficulty”) was 9.8% (95% CI 9.2-10.5%) in women and 9.0% (95% CI 8.1-10.0%) in men, and adjusted to the underlying population 9.5% (95% CI 8.9% - 10.1%) and 8.0% (7.2% - 8.9%) respectively, see [Table 2](#). Prevalence of reporting at least “some difficulty” was 42.2% (95% CI 41.1-43.4%) in women, and 38.5% (95% CI 36.9-40.1%) in men, and adjusted to the underlying population 41.7% (95% CI 40.7-42.7%) and 35.5% (95% CI 34.1-37.0%) respectively.

The most common disabilities reported were difficulty walking at 4.5% (95% CI 4.1-4.9%) and difficulty seeing at 4.2% (95% CI 3.9-4.6%) (*Extended Data*: [Table 1](#)). Prevalence of 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 disability in women than men in every age group, but with overlapping confidence intervals in all but the oldest age group.

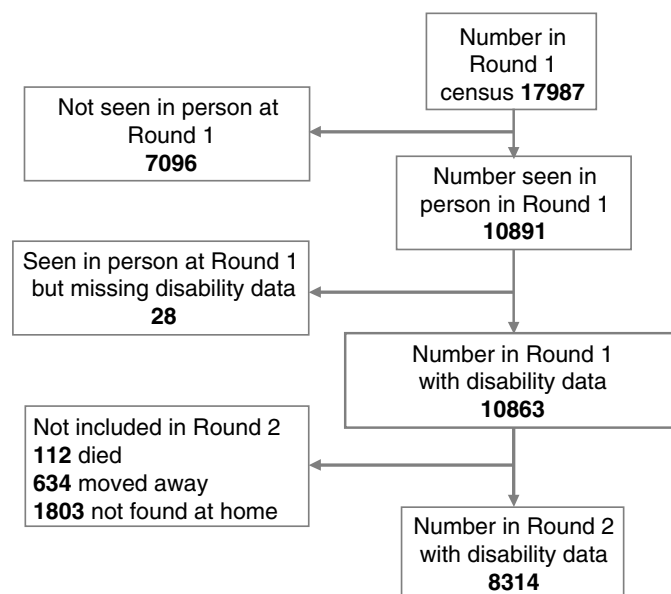


Figure 1. Flow chart of number of individuals participating in each round of the study.

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

	Female		Male	
	Census (n=9786)	Study (n=7437)	Census (n=8201)	Study (n=3426)
	n (%) ¹	n (%)	n (%)	n (%)
Age group				
18–34	5146 (52.6)	3817 (51.3)	4478 (54.6)	1545 (45.1)
35–44	1876 (19.2)	1478 (19.9)	1599 (19.5)	711 (20.8)
45–54	1105 (11.3)	814 (10.9)	935 (11.4)	443 (12.9)
55–64	781 (8.0)	606 (8.1)	552 (6.7)	306 (8.9)
65–59	280 (2.9)	213 (2.9)	192 (2.3)	105 (3.1)
70–74	197 (2.0)	173 (2.3)	142 (1.7)	101 (2.9)
75–79	201 (2.1)	165 (2.2)	154 (1.9)	96 (2.8)
80+	200 (2.0)	171 (2.3)	149 (1.8)	119 (3.5)
Missing	0	0	0	0
Education				
None	378 (3.9)	296 (4.0)	104 (1.3)	69 (2.0)
Primary (part or completed)	6328 (65.1)	4980 (67.4)	3967 (48.6)	1833 (53.7)
Secondary (part or completed)	2529 (26.0)	1759 (23.8)	3449 (42.2)	1265 (37.1)
Tertiary	480 (4.9)	351 (4.8)	646 (7.9)	247 (7.2)
Missing	71	51	35	12
Occupation				
Not working	1152 (11.9)	621 (8.4)	1503 (18.4)	391 (11.5)
Manual work	130 (1.3)	89 (1.2)	1084 (13.3)	387 (11.3)
Farmer/ fisherman	7206 (74.4)	5721 (77.7)	4643 (56.8)	2327 (68.2)
Non-manual work ²	1192 (12.3)	930 (12.6)	939 (11.5)	309 (9.1)
Missing	106	76	32	112
Union status				
Not in a union ³	3383 (34.6)	2343 (31.5)	2637 (32.2)	870 (25.4)
In a union	6395 (65.4)	5090 (68.5)	5552 (67.8)	2553 (74.6)
Missing	8	4	12	3
BMI (kg/m²)⁴				
<18.5 (underweight)	620 (7.1)	479 (7.1)	640 (9.6)	295 (10)
18.5–24.9 (healthy weight)	5629 (64.9)	4314 (64.3)	5400 (80.9)	2356 (79.8)
25–29.9 (overweight)	1768 (20.4)	1398 (20.8)	550 (8.2)	266 (9.0)
30+ (obese)	658 (7.6)	518 (7.7)	83 (1.2)	35 (1.2)
Missing	1111	728	1528	474
Hypertension⁵				
No hypertension	6288 (85.8)	4874 (85.3)	4641 (86.3)	2026 (82.4)
Hypertension	1041 (14.2)	837 (14.7)	737 (13.7)	434 (17.6)
Missing	2457	1726	2823	966

	Female		Male	
	Census (n=9786)	Study (n=7437)	Census (n=8201)	Study (n=3426)
	n (%) ¹	n (%)	n (%)	n (%)
Diabetes⁶				
No diabetes	6401 (98.2)	4990 (98.3)	4536 (98.2)	2057 (97.5)
Diabetes	117 (1.8)	87 (1.7)	81 (1.8)	53 (2.5)
Missing	3268	2360	3584	1316
HIV status⁷				
Negative	6678 (88.1)	5134 (87.7)	4971 (90.4)	2164 (89.0)
Positive	902 (11.9)	719 (12.3)	527 (9.6)	267 (11.0)
Missing	2206	1584	2703	995

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.

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

	Women					Men				
	Total	Reporting at least "some difficulty"		Reporting at least "a lot of difficulty"		Total	Reporting at least "some difficulty"		Reporting at least "a lot of difficulty"	
		n	% (95% CI)	n	% (95% CI)		n	% (95% CI)	n	% (95% CI)
Overall										
Crude prevalence	7437	3142	42.2 (41.1-43.4)	731	9.8 (9.2-10.5)	3426	1318	38.5 (36.9-40.1)	308	9.0 (8.1-10.0)
Standardised to population structure			41.7 (40.7-42.7)		9.5 (8.9-10.1)			35.5 (34.1-37.0)		8.0 (7.2-8.9)
Age group										
18-34	3817	907	23.8 (22.4-25.1)	137	3.6 (3.0-4.2)	1545	321	20.8 (18.8-22.9)	48	3.1 (2.3-4.1)
35-44	1478	605	40.9 (38.5-43.5)	90	6.1 (5.0-7.4)	711	228	32.1 (28.7-35.6)	34	4.8 (3.4-6.6)
45-54	814	525	64.5 (61.1-67.7)	100	12.3 (10.2-14.7)	443	237	53.5 (48.8-58.1)	39	8.8 (6.5-11.8)
55-64	606	454	74.9 (71.3-78.2)	97	16.0 (13.3-19.1)	306	184	60.1 (54.5-65.5)	47	15.4 (11.7-19.8)
65-69	213	176	82.6 (76.9-87.1)	49	23 (17.8-29.1)	105	74	70.5 (61.1-78.4)	18	17.1 (11.1-25.6)
70-74	173	163	94.2 (89.6-96.9)	68	39.3 (32.3-46.8)	101	80	79.2 (70.2-86.0)	34	33.7 (25.1-43.4)
75-79	165	147	89.1 (83.3-93.0)	81	49.1 (41.5-56.7)	96	83	86.5 (78.1-92)	34	35.4 (26.5-45.5)
80+	171	165	96.5 (92.4-98.4)	109	63.7 (56.3-70.6)	119	111	93.3 (87.1-96.6)	54	45.4 (36.7-54.4)

	Women					Men				
	Total	Reporting at least "some difficulty"		Reporting at least "a lot of difficulty"		Total	Reporting at least "some difficulty"		Reporting at least "a lot of difficulty"	
		n	% (95% CI)	n	% (95% CI)		n	% (95% CI)	n	% (95% CI)
Education										
None	296	221	74.7 (69.4-79.3)	99	33.4 (28.3-39.0)	69	50	72.5 (60.8-81.7)	19	27.5 (18.3-39.2)
Primary (part or completed)	4980	2303	46.2 (44.9-47.6)	541	10.9 (10.0-11.8)	1833	800	43.6 (41.4-45.9)	199	10.9 (9.5-12.4)
Secondary (part or completed)	1759	501	28.5 (26.4-30.6)	70	4.0 (3.2-5.0)	1265	386	30.5 (28.0-33.1)	75	5.9 (4.8-7.4)
Tertiary	351	88	25.1 (20.8-29.9)	12	3.4 (2.0-5.9)	247	77	31.2 (25.7-37.2)	14	5.7 (3.4-9.3)
Occupation										
Not working	621	306	49.3 (45.4-53.2)	165	26.6 (23.2-30.2)	391	138	35.3 (30.7-40.2)	78	19.9 (16.3-24.2)
Manual work	89	33	37.1 (27.7-47.5)	5	5.6 (2.4-12.8)	387	152	39.3 (34.5-44.2)	20	5.2 (3.4-7.9)
Farmer/ fisherman	5721	2430	42.5 (41.2-43.8)	491	8.6 (7.9-9.3)	2327	928	39.9 (37.9-41.9)	192	8.3 (7.2-9.4)
Non-manual work	930	335	36.0 (33.0-39.2)	53	5.7 (4.4-7.4)	309	96	31.1 (26.2-36.4)	16	5.2 (3.2-8.3)
Union										
Not in a union	2343	1280	54.6 (52.6-56.6)	410	17.5 (16.0-19.1)	870	257	29.5 (26.6-32.7)	69	7.9 (6.3-9.9)
In a union	5090	1862	36.6 (35.3-37.9)	321	6.3 (5.7-7.0)	2553	1060	41.5 (39.6-43.4)	239	9.4 (8.3-10.6)

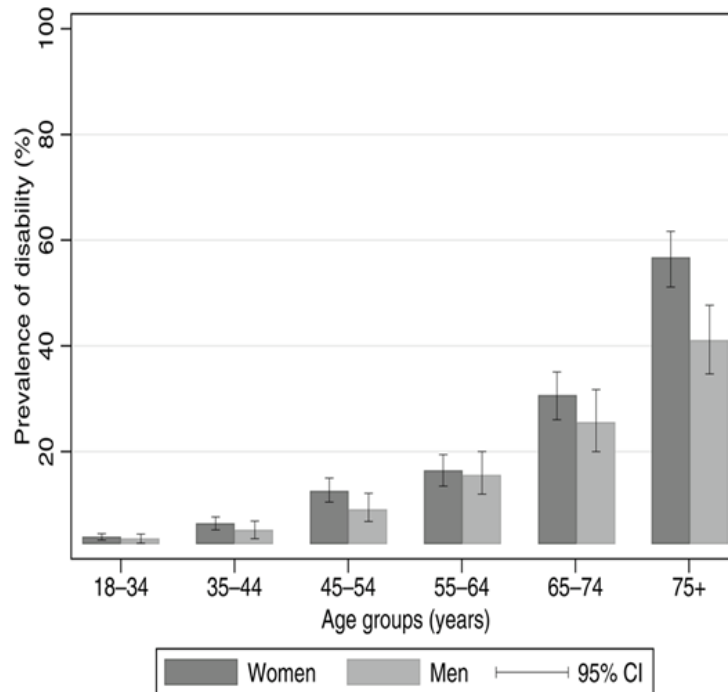


Figure 2. Age and sex specific prevalence of self-reported disability, defined as reporting at least "a lot of difficulty" in any domain.

We found that obesity and diabetes were associated with 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. In sensitivity analysis, we found that these relationships were similar when we excluded participants whose BMI was measured later than the interview date (Extended Data: Table 2). Diabetes was associated with 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 disability (Extended Data: Table 3).

When using reports of at least “some difficulty” as the disability outcome in sensitivity analysis, the relationship between BMI and disability in women remained: women with higher BMI had more than twice the odds of reporting disability than those with healthy BMI (Extended Data: Table 4); but there was no association between diabetes and disability.

Figure 3 shows that age-specific prevalence of disability appeared to be higher with obesity and diabetes than with hypertension, and lower with HIV-infection than any of the other

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

		Number reporting difficulty ¹	Bivariate analysis – Model 1*		Multivariate analysis – Model 2**		Multivariate analysis – Model 3***	
			OR (95% CI)	p-value	OR (95% CI)	p-value	OR (95% CI)	p-value
BMI (kg/m²)								
Women	<18.5 kg/m ²	51/479	0.84 (0.65-1.09)	0.005	0.66 (0.43-1.01)	0.005		
	18.5-24.9 kg/m ²	356/4314	1		1			
	25-29.9 kg/m ²	152/1398	1.24 (1.03-1.50)		1.28 (1.00-1.63)			
	30+ kg/m ²	78/518	1.40 (1.07-1.83)		1.39 (1.01-1.92)			
Men	<18.5 kg/m ²	41/295	1.16 (0.78-1.70)	0.10	1.20 (0.75-1.93)	0.16		
	18.5-24.9 kg/m ²	184/2356	1		1			
	25-29.9 kg/m ²	37/266	1.36 (0.91-2.03)		1.21 (0.75-1.96)			
	30+ kg/m ²	9/35	2.62 (1.14-6.02)		2.93 (1.15-7.46)			
Hypertension								
Women	No hypertension	366/4874	1	0.80			1	0.40
	Hypertension	215/837	1.03 (0.82-1.30)				0.90 (0.71-1.15)	
Men	No hypertension	144/2026	1	0.13			1	0.28
	Hypertension	90/434	1.30 (0.93-1.81)				1.21 (0.86-1.71)	
Diabetes								
Women	No diabetes	478/4990	1	0.37			1	0.09
	Diabetes	20/87	1.29 (0.74-2.24)				1.11 (0.63-1.97)	
Men	No diabetes	190/2057	1	0.007			1	0.003
	Diabetes	18/53	2.47 (1.32-4.64)				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	188/2164	1	0.83				
	HIV positive	26/267	1.05 (0.67-1.65)					

*Model 1: Bivariate analysis adjusted for age only (as linear variable) **Models adjusted for age (as a linear variable), hypertension (hypertension/ no hypertension/ unknown), and diabetes (diabetes/ no diabetes/ unknown diabetes) ***Models adjusted for age (as a linear variable) and BMI (<18.5 kg/m²/ 18-24.9 kg/m²/ 25-29.9 kg/m²/ 30+kg/m²)

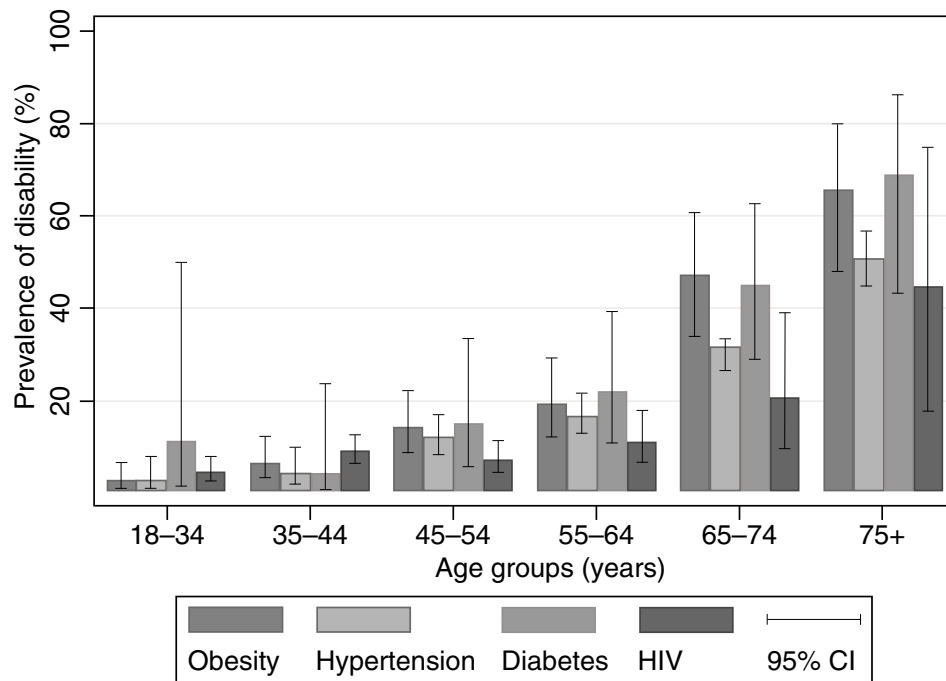


Figure 3. Age-specific prevalence of self-reported disability with obesity, hypertension, diabetes, and HIV-infection.

conditions examined. However, the confidence intervals were overlapping.

Table 4 shows whether self-reported disability status in each disability domain changed over the two rounds. Incident disability was between 0.3% (95% CI 0.2-0.4%) for difficulty communicating and 2.3% (95% CI 2.0-2.6%) for difficulty walking. Between 61.9% (95% CI 40.2-79.7%) to 90.6% (95% CI 85.4-94.1%) of disability resolved between 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 5).

Discussion

Around one in ten study participants reported disability, most commonly difficulty walking or seeing. Prevalence was higher 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. In 2010–2011, the Washington Group short set questions were asked to adults aged 15 and over in the Malawi Integrated Household Survey, where a much lower prevalence of disability was found: 1.4% of people had at least “a lot of difficulty” in at least one domain. The difference may be explained by a different proportion of responses given by a proxy (as proxy respondents are likely to underestimate the prevalence of functional difficulties), or differences in the way the survey questions were posed. Alternatively, there may have been a different age structure among respondents in the two surveys⁵.

The discourse on disability in low and middle income countries (LMIC) links disability closely with poverty^{13–15}. Therefore, in Malawi, a poor and food-insecure country¹⁶, disability might be expected to be associated with under-nutrition and low BMI. However, our findings demonstrated a stepwise increase in odds of disability with increasing BMI, particularly among women, independent of hypertension and diabetes, and was present for both disability as defined by at least “a lot of difficulty” and at least “some difficulty”. 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 osteoarthritis¹⁷. Obesity is

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	Incident disability	Resolution of disability
		n % (95% CI)	n % (95% CI)	n % (95% CI)	n % (95% CI)	n % (95% CI)	n % (95% CI)
Difficulty seeing	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%	137/7921 1.7% (1.5-2.0%)	
	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%)		305/388 78.6% (74.2-82.4%)
	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%)	37/8233 0.4% (0.3-0.6%)	
	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%)		48/75 64.0% (52.6-74.0%)
	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%)		
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%)	181/7912 2.3% (2.0-2.6%)	
	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%)		279/375 70.6% (65.9-74.9%)
	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%)	109/8109 1.3% (1.1-1.6%)	
	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%)		164/181 90.6% (85.4-94.1%)
	Can't do at all	0/1 0%	0/1 0%	1/1 100%	0/1 0%		

	Round 1	No difficulty	Some difficulty	A lot of difficulty	Can't do at all	Incident disability	Resolution of disability
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%)	22/8264 0.3% (0.2-0.4%)	
	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%)	13/21 61.9% (40.2-79.7%)	
	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%)	68/8134 0.8% (0.7-1.1%)	
	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%)	139/159 87.4% (81.3-91.7%)	
	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

well-recognised to be associated with disability in high income countries (HIC)¹⁸⁻²⁰, but this association has only rarely been seen in LMIC^{21,22}. Similarly, while disability is strongly associated with diabetes in HIC²³⁻²⁵, evidence in LMIC has been less consistent²⁶⁻²⁸. 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 controlled²⁹, eye disease develops early in the disease course³⁰. Both obesity and diabetes are highly prevalent²⁹, and should be recognised as potentially important drivers for disability among this population. This may be the first study investigating the relationship between disability and disease states through biomarkers other than HIV infection in LMIC³¹. Systematic reviews of the association of disability with BMI, hypertension and diabetes in LMICs would be a useful contribution to the literature to help elucidate these associations further.

Our finding that hypertension was not associated with disability was in keeping with a meta-analysis analysing the contribution of chronic diseases to disability in older people in LMIC²⁸. The literature on HIV infection and disability in sub-Saharan Africa is mixed: HIV has been shown to be associated with frailty^{32,33}, a syndrome closely linked to disability³⁴, and a systematic review found that in 27 of 37 studies, people living with HIV had lower levels of functioning than those without

HIV³¹. 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 improved³⁵.

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. This movement of people in and out of disability status was also seen from similar panel data using the Washington Group short set in Ethiopia and Uganda⁵. While some people did move from “can’t do at all” to “no difficulty” in the domains of walking, communicating, and self-care, the numbers were very small and this may have represented acute illness that resolved or impairments that were successfully treated.

Our study has some important strengths. Due to the large sample size and collection of data on other health states, we can obtain precise estimates of 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 clinical assessment of impairment or function. Comparisons of self-reported disability between age-groups, sexes, and externally to other populations may be less valid than when using clinical assessment of impairments as there may be cultural differences between willingness to report disability or different levels of stoicism (or expected function)^{36,37}. 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. Our use of this tool therefore meant that we were not able to assess participation restriction, which is a fundamental component of the ICF model of disability. However, the brevity of the WG questions does allow the questions to be easily added to existing surveys, and we did also report on employment inclusion and marital status as proxies for participation. 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 clinics¹¹. 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 even in this very poor rural setting there are significant independent associations between both obesity and diabetes and 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.0000096138>. Data are available under the terms of the [Creative Commons Attribution 3.0 International license](#) (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 BMI and chronic disease: Extended Data. <https://doi.org/10.7910/DVN/IAELBG39>.

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 and self-reported disability (excluding BMI measurements taken after the date of the study interview)
3. Extended Data Table 3: Logistic regression analysis of the association between BMI, hypertension, diabetes, and HIV with self-reported disability in different domains at Round 1
4. Logistic regression analysis of the association between BMI, hypertension, diabetes, and HIV infection with self-reported disability in any domain at Round 1 (disability defined as at least "some difficulty" in any domain)
5. 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).

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Nawi Ng 

Department of Public Health and Community Medicine Institution of Medicine, Sahlgrenska Academy, University of Gothenburg, Gothenburg, Sweden

Thank you for the invitation to review this revised manuscript. I commend the authors' effort in revising and improving the quality of the paper. As much as I would like to support this research to be indexed, I still have significant concern about the quality of the paper.

The validity of self-reported disability data: I appreciate the authors' effort to assess the "consistency" of self-reported disability data collected in Round 1 and Round 2 of the disability survey (one year apart). By comparing response patterns in Round 1 and Round 2, the authors estimated the incidence of disability and resolution of disability. If the reporting of disability is valid and reliable, these estimates will give a picture of how disability changes over time. Table 4, in contrast, shows that the self-reported disability seems to be inconsistent over time. In my initial review, I raised the concern about 9.1% of respondents who could not walk at all in the baseline but reported no difficulty in the follow-up. The authors argued that these represent only 2 out of 22 individuals, hence is understandable. However, how could we interpret the data in Table 4 which show 78.6% of those with a lot of difficulty in seeing (the question asks, "Do you have difficulty seeing, **even if wearing glasses?**") had their seeing difficulty resolved within one year? The same pattern was observed in other domains of disability. These findings are unexpected in rural Malawi which, according to the authors, was a "very poor rural setting" where one does not expect interventions of any kinds to happen during the study period. By the way, the term "consistency" still appears in the objective (in Abstract and main text) and the title for Table 4.

Lack of clarity in the multivariate analyses (Table 3): There are two issues about Table 3 that I could not understand. **Firstly**, according to the authors, Model 2 is a multivariate model regressing disability on body mass index and controlling for hypertension, diabetes and age. Model 3 is a multivariate model regression disability on hypertension and diabetes and controlling for body mass index and age. Aren't these two models the same model? Why were they referred to as different models? **Secondly**, it is unclear how the authors could obtain the results for BMI, hypertension and diabetes separately for men and women in a single model (Model 2 or Model 3). The results in Table 3 could only be obtained by stratifying the analysis by sex (if so, the model should be referred to as Model 2A for men and Model 2B for women). Even if the authors had included an interaction term between sex and BMI (not declared in

the paper), they would have only one reference category, not two as reported in Table 3 (BMI 18.5-24.9 for men and women). In brief, it is difficult to understand what Table 3 represents, and this puts doubt on the main findings and the conclusion of this study.

Potential biases influencing the conclusions of the study: I appreciate the effort of the authors to link data from multiple sources collected 1-3 years before the baseline survey of disability. In my earlier review, I raised the concern about missing data and selection bias due to missing not at random. It is insufficient to acknowledge these issues as a limitation of the study, especially when the potentially biased results could influence the conclusion of the study. How sure could the authors conclude that hypertension and HIV are not associated with disability, knowing that those with severe hypertension or late-stage HIV (measured a few years before the disability survey) might have died already before the disability survey started? Hence, those who participated in the survey had less severe hypertension or early stage of HIV, and hence experienced less severe disability (survival bias).

A minor issue on the data linkage – how did the researchers handle the data, for example, the body mass index, if the individual data on BMI was missing from the census survey data but existed in more than one other studies (it could happen). Which data value was considered in the current study?

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.

Reviewer Report 09 December 2019

<https://doi.org/10.21956/wellcomeopenres.17087.r37255>

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Sophie Mitra

Fordham University, New York, NY, USA

The paper has very much improved. It is more focused and clearly written and makes a significant contribution to the literature.

There are a few things that need to be revised.

1. The introductory background is very useful. A few sentences and references on the prevalence of chronic conditions in Malawi, for instance on the recent rise in obesity would add to the useful background.
2. The results are presented as applying to all of Malawi. This is for instance the case in the abstract and in the conclusion starts with “Self-reported disability prevalence in rural Malawi is around 10%

in adults". Yet, the data under use is not nationally representative. The authors need to carefully edit so that the results are presented as for this study, based within the rural Karonga Health and Demographic Surveillance Site.

3. I recommend that Table 1 includes descriptive statistics for all variables used in the study, including obesity.
4. The authors do not give results on the association between disability and socioeconomic status, which as they note, has been an important issue in the literature. At least, a mention of their results on this, would be useful. This is particular in light of the association found between obesity and disability for women.
5. For the Malawi results using the Malawi Integrated Household Survey 2010/11 and for the Uganda and Ethiopia results on changes in disability status over time, the correct reference is Mitra S: Disability, Health and Human Development. Palgrave MacMillan: New York, and not the article in AJPA.
6. Regarding the Malawi results using the Malawi Integrated Household Survey 2010/11, the authors of this paper mention the potentially different age structures of the population in the national survey compared to their survey. They should actually check on that given the results in the book above (Table 4.4).
7. The wording of the abstract needs to be carefully edited for accuracy. For instance, the association of obesity and disability is found only for women, but is presented as a general result in the abstract.
8. The authors note that "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. Our use of this tool therefore meant that we were not able to assess participation restriction, which is a fundamental component of the ICF model of disability. However, the brevity of the WG questions does allow the questions to be easily added to existing surveys, and we did also report on employment inclusion and marital status as proxies for participation". The WG questions combined with other questions for instance on employment can be used to assess participation restrictions. Hence, this text is unnecessary. It was not within the scope of the paper to assess participation restriction, which is okay.
9. Sometimes in the text, LMIC need to be switched to plural.

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.

Version 1

Reviewer Report 08 August 2019

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

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Nawi Ng 

Department of Public Health and Community Medicine Institution of Medicine, Sahlgrenska Academy, University of Gothenburg, Gothenburg, Sweden

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 word, 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.

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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, University College London, London, UK

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 word, 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

<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

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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 Prynne, University College London, London, UK

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