


# BMJ Open Factors associated with the longer-term unmet supportive care needs of stroke survivors in Ethiopia: a multicentre cross-sectional study

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## ABSTRACT

**Objectives** To assess the magnitude of the longer-term unmet supportive care needs and associated factors among adult stroke survivors.

**Design** Institutional-based multicentre cross-sectional study.

**Setting** Between 1 March 2020 and 31 May 2020, in Addis Ababa, Ethiopia.

**Participants** Adult stroke survivors (aged  $\geq 18$  years,  $n=422$ ), diagnosed with a stroke at least 6 months before the study period and who started regular follow-up at the neurology outpatient clinics in Addis Ababa, Ethiopia.

**Main outcome measures** Self-reported longer-term supportive care needs.

**Results** Two hundred and twenty-six (53.6%) stroke survivors had longer-term unmet supportive care needs, and 196 (46.4%) survivors had no longer-term unmet supportive care needs. Information need about stroke was reported by 416 (98.6%), and how to travel on public transportation was reported by 340 (80.6%) survivors. These were the most frequently reported unmet needs. Stroke survivors' longer-term unmet supportive care needs were significantly associated with being hypertensive with (adjusted OR (AOR) 4.59; 95% CI 2.61 to 8.07), having heart disease with (AOR 1.94; 95% CI 1.19 to 3.82), moderate and above level of disability according to the modified Rankin Scale score with (AOR 26.4; 95% CI 8.61 to 80.92) and unable to use the physiotherapy service with (AOR 2.85; 95% CI of 1.63 to 4.99).

**Conclusions** There are significant longer-term unmet supportive care needs among adult stroke survivors. The factors associated with longer-term unmet supportive care needs were; having comorbidities, moderate and above level of disability according to the modified Rankin Scale score and unable to use the physiotherapy service. The development of appropriate services to address the longer-term unmet supportive care needs of stroke survivors is warranted.

## INTRODUCTION

Globally, stroke is the second-leading cause of death following ischaemic heart disease, being responsible for 8.76 million deaths and taking lives every five seconds. Stroke is the second most common cause of adult disability

## Strengths and limitations of this study

- This was the first local study using the standardised instrument for measuring stroke patients' longer-term unmet needs and this can serve as baseline information for further research in Ethiopia and sub-Saharan Africa.
- The previous studies were mainly focused on the descriptive summary of the unmet needs, but this study tried to identify the factors associated with stroke survivor's longer-term unmet needs.
- Stroke survivors coming to the facility might have more comorbidities and thus report more unmet needs than stroke survivors in the community. Even though the sample size is adequate, generalisation is limited because of the sampling method used.
- Since qualitative data was not collected, a detailed understanding of the longer-term unmet needs among stroke survivors is limited.

(4.6%) of the global disability-adjusted life-years.<sup>1</sup> Without significant interventions, the global stroke mortality is estimated to rise to 7.8 million deaths per year by the end of 2030.<sup>2</sup> The global economic cost of adult stroke is more than 25 billion dollars per year.<sup>3</sup>

Supportive care is defined as, rendering essential services that satisfy stroke patients' physical, psychological, social, informational and spiritual needs over the entire illness trajectory. Supportive care is an essential buffering component of stroke survivors that helps to regain emotional stability, social adjustment, cognitive function, body image, future perspective and physical recovery.<sup>4</sup>

In sub-Saharan Africa (SSA), stroke primarily affects the young and productive segment of the population.<sup>5 6</sup> The development of appropriate service provision is limited by the lack of vigorous estimates of longer-term outcomes after stroke and the prevalence of stroke survivors in SSA



was reported to be 14.6/1000 people.<sup>7</sup> High burden of uncontrolled vascular risk factors due to low screening and treatment modalities, uncoordinated and fragmentary acute stroke care, and limited rehabilitation services were described as factors associated with poor prognosis after Stroke.<sup>5,7</sup> The increase in the magnitude of Stroke, thus calls the urge to identify their unmet needs to accelerate their recovery.<sup>8</sup>

In SSA, the physiotherapists to population ratio range from 0.1/100 000 people in Ethiopia to 6.7/100 000 people in South Africa.<sup>5</sup> There is a high mismatch in the longer-term stroke rehabilitation care need and delivery. Longer-term supportive care service delivery should be patient-oriented and designed compatible with the local situation.<sup>9</sup> Therefore, assessing the needs of stroke survivors is essential to improve stroke survivors' quality of life.<sup>9,10</sup> Even though the unmet need for supportive care for cancer and chronic kidney failure patients is documented, much attention was not given to the supportive care services among stroke survivors.<sup>4</sup>

To the best of our knowledge, we did not get studies conducted in SSA, including in Ethiopia, which determines the longer-term unmet supportive care needs, and associated factors among adult stroke survivors. This study intended to assess the magnitude of the longer-term unmet supportive care needs, and associated factors among adult stroke survivors in Tikur Anbessa Specialised Hospital (TASH) and Saint Paul's Hospital Millennium Medical College (SPHMMC), Addis Ababa, Ethiopia.

## METHODS AND MATERIALS

The study was conducted in TASH and SPHMMC in Addis Ababa, the capital city of Ethiopia. TASH is the first largest government-owned hospital serving as a teaching hospital of Addis Ababa University and a major referral centre from all over the country. TASH provides service to different Neurologic cases at the neurology outpatient department (OPD) twice a week and allocated one additional day to treat stroke survivors in the OPD. SPHMMC is the second-largest hospital in Ethiopia following TASH. It treats neurologic cases 4 days a week in the neurology OPD. The study was conducted from 1 March 2020 to 31 May 2020.

### Study design

An institutional-based multicentre cross-sectional study was conducted.

### Participants

Those adult stroke survivors (aged  $\geq 18$  years) who were diagnosed with stroke at least 6 months before the study period and who started follow-up at the neurology OPD of TASH and SPHMMC were considered as the study population. Those stroke survivors who were not able to represent themselves or who did not have anyone to represent them as a caregiver were excluded from the study.

**Table 1** Sociodemographic characteristics of adult stroke survivors receiving routine follow-up services Addis Ababa, Ethiopia, 2020 (n=422)

Variables	Categories	Frequency	%
Age, median (25–75th), years		54.5 (43–62)	
Age (in years)	<45	112	26.5
	45–54	99	23.4
	55–64	118	28
	65–74	55	13
	75–84	34	8.1
	>85	4	1
Gender	Male	243	57.6
	Female	179	42.4
Residence	Urban	338	80.1
	Rural	84	19.9
Region	Addis Ababa	307	72.7
	Oromia	77	18.3
	Amhara	19	4.5
	Others*	19	4.5
Marital status	Married	282	66.8
	Never married	50	11.9
	Divorced	32	7.6
	Common law	58	13.7
Religion	Orthodox	323	76.5
	Protestant	45	10.7
	Catholic	39	9.2
	Muslim	15	3.6
Educational level	Unable to read and write	40	9.5
	Able to read and write	80	18.9
	Primary school completed	56	13.3
	Secondary school completed	101	23.9
	Diploma or degree	107	25.4
	Masters and above	38	9
Occupational status (n=419)	Farmer	59	14.1
	Government employee	138	32.9
	Trader	53	12.7
	NGO	96	22.9
	Unemployed	39	9.3
	Housewife	15	3.6
	Others†	19	4.5
Monthly income (In US\$) (n=419)	<12	30	7.2
	12–60	120	28.6
	60–120	141	33.6
	120–240	118	28.2
	>240	10	2.4
Family size (n=410)	$\leq 5$ members	276	67.3
	>5 members	134	32.7

\*Others: Afar, Southern Nations, nationalities and peoples regional state.

†Student and daily labourer.

NGO, non-governmental organisation; USD, United States Dollar.

**Table 2** Clinical characteristics of adult stroke survivors receiving routine follow-up services Addis Ababa, Ethiopia, 2020 (n=422)

Patient profile	Categories	Frequency	%
Stroke type	Ischaemic	360	85.3
	Haemorrhagic	27	6.4
	SAH	35	8.3
Time since last stroke attack (n=420)	6 months	50	11.9
	6–12 months	107	25.5
	>12 months	263	62.6
History of recurrence	No	230	54.5
	Yes	192	45.5
History of hypertension	Yes	259	61.4
	No	163	38.6
History of diabetes mellitus	No	308	73
	Yes	114	27
History of heart diseases	No	340	80.6
	Yes	82	19.4
Level of disability according to mRS	No symptoms at all	59	14
	No significant disability despite symptoms	159	37.7
	Slight disability	122	28.9
	Moderate disability	44	10.4
	Moderately severe disability	22	5.2
	Severe disability	16	3.8

mRS, modified Rankin Scale; SAH, Subarachnoid hemorrhage.

### Sample size determination and sampling technique

The sample size was determined by applying a single population proportion formula using Epi Info V.7.2.4.0 software,<sup>11</sup> with the assumptions of a 95% level of confidence, a 5% margin of error. Since we could not find any previous studies conducted in Africa to determine the longer-term unmet supportive care needs among adult stroke survivors, the sample size was calculated by taking the largest sample size to detect a statistically significant difference. Accordingly, the percent of stroke survivors who have long-term unmet supportive care needs 50%, with these assumptions the sample size was 384, and after adding a 10% non-response rate the final sample size was 422.

### Sampling procedure

A convenience sampling technique was used to select the study participants, accordingly, all adult stroke survivors who were available at the neurology OPDs of TASH and SPHMMC during the study period who meet the inclusion criteria were included in the study.

### Data collection instrument

A pretested structured interviewer-administered questionnaire, which contains the sociodemographic, clinical, neurological factors and the longer-term unmet supportive care needs (LUNs) questions, was used to collect the data. The interviewer-administered questionnaire was prepared in English then translated into the local language (Amharic) and retranslated back to English to maintain its consistency. The level of disability of the stroke survivors was measured by using the modified Rankin Scale (mRS).<sup>12</sup>

The LUNs is a 22-item standardised instrument for measuring stroke patients' longer-term unmet needs.<sup>13</sup> The 22 variables that were included in the LUNS tool were combined into one by calculating the mean, the mean of these variables was further dichotomised by calculating its population mean as having no unmet need and having an unmet need. If a patient-reported an unmet need that was above the population mean, it is considered as having an unmet need. On the other hand, if a patient reports unmet needs below the mean value it was considered as having no unmet need.

### Operational definitions

Stroke survivor: is a person who has had a stroke attack previously and is not currently receiving acute coma care or receiving an inpatient treatment in a hospital setting.<sup>14</sup> Longer-term supportive care needs: These include physical relationships, managing money, accessible holidays, pain, driving, memory, information, employment, benefits, daily occupations, bladder control, mood, adaptations outside, diet, home help, moving house, transportation, adaptations inside, falling, mobility, blood pressure.<sup>15</sup>

Needs: Issues and/or actions that are deemed necessary by the survivor to manage his/her well-being and best quality of care. An unmet need: a problem that was not being addressed or one that was being addressed, but insufficiently. Longer-term unmet need: unmet needs that exist at least after 6-month poststroke.<sup>15</sup> Having longer-term unmet need: having unmet needs that exist at least after 6-month poststroke which are above the calculated mean value.

### Data processing, management and analysis

The collected data was coded and checked for its consistency and completeness up to the end of each data collection period. Before the analysis, the whole data was cleaned and 20% of the data was double-entered randomly to check for data entry errors and Epi Info V.7.2.4.0 software<sup>11</sup> was used for data entry. The entered data was exported to STATA V.14.0 for windows.<sup>16</sup> Descriptive statistics was presented in medians with IQR for numerical variables and categorical variables were presented using frequency and percentages.

The bivariate analysis was done to check the existence of crude association and to select candidate variables, those variables which are clinically important and having ( $p < 0.25$ ) were included in the final model.<sup>17</sup>

**Table 3** The magnitude of unmet supportive care needs among adult stroke survivors receiving routine follow-up services Addis Ababa, Ethiopia, 2020 (n=422)

Longer-term unmet supportive care needs questions	Patient response	
	Yes Frequency (%)	No Frequency (%)
Need information about stroke	416 (98.6)	6 (1.4)
Need blood pressure checkups frequently	273 (64.7)	149 (35.3)
Need help managing pain	192 (45.5)	230 (54.5)
Worsening movement disorders	180 (43)	239 (57)
Afraid of falling again	297 (70.4)	125 (29.6)
Need adaptations/aids inside home	224 (53.1)	198 (46.9)
Need adaptations outside home	212 (50.2)	210 (49.8)
Need advice about driving again	110 (26.1)	312 (73.9)
Need advice on travelling on public transportation	340 (80.6)	82 (19.4)
Need help in completing chores	231 (54.7)	191 (45.3)
Need to move to another home	250 (59.2)	172 (40.8)
Need advice about improving diet	335 (79.4)	87 (20.6)
Need advice about financial management	244 (57.8)	178 (42.2)
Need help to apply for benefits	302 (71.6)	120 (28.4)
Need advice on employment after stroke	306 (72.5)	116 (27.5)
Need help to take a bath and cut my nails	180 (42.7)	242 (57.3)
Need help with my bladder and bowel activities	142 (33.6)	280 (66.4)
Need advice about my physical relationship	208 (49.3)	214 (50.7)
Need help about concentration and mood	306 (72.5)	116 (27.5)
Need help on how to avoid my angry or worry	316 (74.9)	106 (25.1)
Need advice on how to occupy my day better	314 (74.4)	108 (25.6)
Need help with catering during holidays	223 (52.8)	199 (47.2)

Confounding was checked, and percentage change in the regression coefficients ( $\beta$ ) less than 20% reveals an absence of confounder. Interaction for the main effect model was also be checked and partial likelihood ratio test result with  $p > 0.05$  and variance inflation factor less than 10 indicating the non-existence of multicollinearity among the independent variables.

The multivariable binary logistic regression model was used to identify the independent factors associated with longer-term unmet supportive care needs. The summary measures of estimated crude and adjusted ORs (AOR) with 95% CI were presented and p value less than 0.05 was used to declare statistical significance and goodness of fit of the model was assessed by using Hosmer and Lemeshow goodness of fit test. Finally, the results were presented in statements, tables and figure.

## Patient and public involvement

A standard tool was used to collect outcome measures of longer-term unmet supportive care needs (LUNs) questions, was used to collect the data. The interviewer-administered questionnaire was prepared in English then translated into the local language (Amharic) and retranslated back to English to maintain its consistency. The Amharic version was pretested on 10% of the study participants to check the clarity of the questions and receive feedback from the respondents. Consent was received from each participant before the data collection and the data collectors were trained to provide any information or clarification at any time of the interview. Only participants who wish to continue the study after informed consent were included in the study. The study results are disseminated to the neurology OPD of both hospitals to raise awareness on the unmet needs of the patients so that the health professionals will start to give more emphasis on the most reported unmet needs.

## RESULTS

### Sociodemographic characteristics

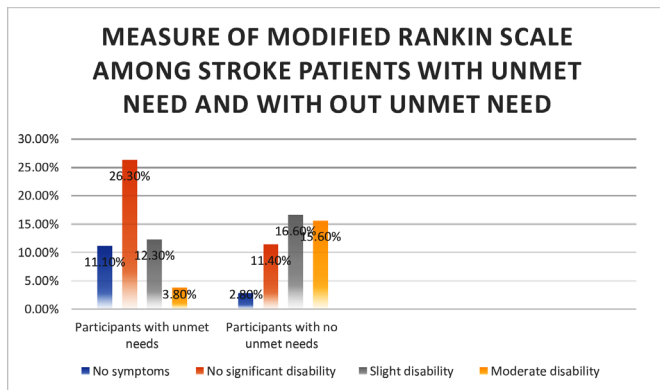
A total of 422 adult stroke survivors were included in this study, making the response rate 100%. Concerning the sex distribution, 243 (57.6%) of the survivors were males. The overall median age of the survivors was 54.5 years with IQR (43-62) years. Three hundred and thirty-eight (80.1%) of the survivors were urban residents and 307 (72.7%) were from Addis Ababa. One hundred and seven (25.4%) of the survivors have a diploma or degree (table 1).

### Clinical characteristics of participants

Ischaemic stroke was diagnosed among 360 (85.3%) stroke survivors. Concerning the time from the last stroke attack, 263 (62.6%) stroke survivors had their last stroke attack for more than a year. History of stroke recurrence was reported among 192 (45.5%) stroke survivors. Hypertension and diabetes mellitus were the most common medical comorbidities reported among 259 (61.4%) and 114 (27%) stroke survivors, respectively. According to the mRS score, 159 (37.7%) of the survivors had no significant disability despite symptoms, whereas 16 (3.8%) of the stroke survivors had a severe disability (table 2).

### Physiotherapy service utilisation

One hundred and fifty-seven (37.2%) stroke survivors used physiotherapy services, and 265 (62.8%) of the survivors do not use physiotherapy services. Among those who used physiotherapy service, 13 (8.3%) were receiving physiotherapy every day excluding weekends and holidays, meanwhile, 56 (35.7%) of the survivors used 2-3 times per week for 30-45 min. On the other hand, 61 (38.8%) of the survivors used physiotherapy less than two times a week, and 27 (17.2%) of the survivors used physiotherapy irregularly. Financial problems, lack of transport service and unsatisfied with the physiotherapy service were the reasons for not using



**Figure 1** Score of modified Rankin Scale among adult stroke survivors with and without long-term unmet supportive care needs receiving routine follow-up services Addis Ababa, Ethiopia, 2020 (n=422).

physiotherapy service reported by 100 (38.2%), 54 (20.6%) and 108 (41.2%) survivors, respectively.

### The magnitude of unmet supportive care needs

All stroke survivors reported at least one unmet need, 416 (98.6%) survivors stated that they need more information about their stroke, why it happened and how to avoid having another one. The next two common unmet needs were, seeking advice on how to use public transportation reported by 340 (80.6%) and seeking advice on modifying their diet reported by 335 (79.4%) (table 3). Two hundred and twenty-six (53.6%) stroke survivors had longer-term unmet supportive care needs (LUNs), and 196 (46.4%) survivors had no longer-term unmet supportive care needs.

### Factors associated with longer-term unmet needs

In the final multivariable binary logistic regression model, after controlling the effect of other confounders, hypertensive stroke survivors are four times more likely to have longer-term unmet supportive care needs than non-hypertensive survivors with (AOR 4.59; 95% CI 2.61 to 8.07). Similarly, those stroke survivors who have heart disease are two times more likely to have long-term unmet supportive care needs than those who do not have heart disease (AOR 1.94; 95% CI 1.19 to 3.82).

Those stroke survivors who have a moderate and above level of disability according to the mRS score have a very significant longer-term unmet supportive care needs than those who have no symptoms at all with (AOR 26.4; 95% CI 8.61 to 80.92) figure 1. Stroke survivors who used physiotherapy services are three times less likely to have longer-term unmet supportive care needs than those who do not use physiotherapy services (AOR 2.85; 95% CI 1.63 to 4.99) (table 4).

## DISCUSSION

### Background

This study assessed the magnitude of the longer-term unmet supportive care needs and its associated factors among adult stroke survivors in TASH and SPHMMC. We found that being hypertensive, having heart disease,

moderate and above level of disability according to the mRS score, unable to use the physiotherapy service were the factors associated with the higher experience of the longer-term unmet supportive care needs.

### Sociodemographic characteristics

The median age of the stroke survivors who were included in this study was 54.5 years with an IQR of 43–62 years with males being the majority. This is consistent with several hospital-based studies by which stroke seems to be affecting the younger age groups within this decade.<sup>18</sup> Even though rural residents were two times more likely to have unmet supportive care needs, we did not get a statistically significant association. This higher unmet need was in line with a study conducted in England by which participants living in less accessible areas to therapy reported more unmet needs.<sup>15</sup> This might be caused by the lack of health infrastructure and long distance from the rural area to the health facility.

### Clinical characteristics

History of hypertension was reported by 61% of stroke survivors. Similarly, another study conducted in Addis Ababa Ethiopia mentioned that hypertension occurred in 65% of the total study participants irrespective of their stroke type. In this study, the history of heart disease was significantly associated with longer-term unmet supportive care needs, this finding goes in line with a study conducted in Europe by which patients who had comorbidities reported more unmet needs than the others.<sup>19</sup>

The level of disability according to the mRS was significantly associated with longer-term unmet needs. This finding was consistent with a study conducted in Germany by which the level of disability of stroke survivors was significantly associated with unmet psychosocial supportive care needs.<sup>20</sup>

Physiotherapy utilisation was reported by 37.2% of the participants in this study. Similarly, a study which was conducted in West Africa stated that the physiotherapy utilisation of stroke survivors is low.<sup>9</sup> In this study, not being able to afford the services provided, a long distance from home to the physiotherapy utilisation centres, transportation-related issues, and unsatisfactory services were identified as reasons for not using physiotherapy.

### The magnitude of unmet needs

The magnitude of unmet supportive care needs in this study ranges from 26.1% (driving needs) to 98.6% (information needs). Similarly, a study conducted in Germany found that 54% of survivors reported they need more information about the cause of their stroke and prevention of recurrence.<sup>20</sup> In our study, 54% reported needs related to pain management (they have constant pain and nothing seems to ease it). On the other hand, a study conducted in England stated that only 39.5% of stroke survivors reported unmet needs regarding pain.<sup>10</sup> This

**Table 4** Factors associated with longer-term unmet supportive care needs among adult stroke survivors, Addis Ababa, Ethiopia, 2020 (n=422)

Patient profile	Categories	Longer-term supportive care needs		COR	P value	Aor (95% CI)	P value
		Having unmet need	No unmet need				
Age (in years)	<45	63 (14.9)	49 (11.6)	<b>Ref (1)</b>			
	45–54	59 (14)	40 (9.5)	0.87	0.62	0.59 (0.27 to 1.26)	0.17
	55–64	61 (14.5)	57 (13.5)	1.20	0.49	0.99 (0.47 to 2.07)	0.98
	65–74	32 (7.6)	23 (5.5)	0.92	0.81	0.38 (0.15 to 1.97)	0.17
	≥75	11 (2.6)	27 (6.3)	3.16	0.005	1.72 (0.62 to 4.76)	0.29
Gender	Male	129 (30.6)	114 (27)	<b>Ref (1)</b>			
	Female	97 (23)	82 (19.4)	0.96	0.82		
Residence	Urban	193 (45.7)	145 (34.4)	<b>Ref (1)</b>			
	Rural	33 (7.8)	51 (12.1)	2.06	<b>0.004</b>	2.54 (0.93 to 6.89)	0.07
Region	Addis Ababa	171 (40.5)	136 (32.2)	<b>Ref (1)</b>			
	Out of Addis Ababa	55 (13)	60 (14.3)	1.37	<b>0.15</b>	0.96 (0.38 to 2.40)	0.93
Marital status	Married	149 (35.3)	133 (31.5)	<b>Ref (1)</b>			
	Never married	20 (4.7)	30 (7.1)	1.68	<b>0.1</b>	1.56 (0.68 to 3.59)	0.29
	Divorced	12 (2.8)	20 (4.7)	1.87	<b>0.1</b>	0.73 (0.26 to 2.05)	0.09
	Common law	45 (10.7)	13 (3.1)	0.32	<b>0.001</b>	0.50 (0.23 to 1.11)	0.55
Educational level	Able to read, write and above	204 (48.3)	178 (42.2)	<b>Ref (1)</b>			
	Unable to read and write	22 (5.2)	18 (4.3)	0.94	0.85		
Occupational status (n=419)	Government employee	65 (15.5)	73 (17.4)	<b>Ref (1)</b>			
	Non-government employee	159 (38)	122 (29.1)	0.68	<b>0.07</b>	0.69 (0.31 to 1.04)	0.2
Monthly income (In US\$) (n=419)	>120	71 (17)	57 (13.6)	<b>Ref (1)</b>			
	≤120	153 (36.5)	138 (32.9)	1.12	0.59		
Family size (n=410)	≤5 members	141 (34.4)	135 (32.9)	<b>Ref (1)</b>			
	>5 members	73 (17.8)	61 (14.9)	0.87	0.52		
Stroke type	Ischaemic	196 (46.5)	164 (38.9)	<b>Ref (1)</b>			
	Haemorrhagic	14 (3.3)	13 (3.1)	1.11	0.79		
	SAH	16 (3.8)	19 (4.5)	1.41	0.33		
Time since last stroke attack (n=420)	>12 months	153 (36.4)	110 (26.2)	<b>Ref (1)</b>			
	<12 months	72 (17.1)	85 (20.2)	1.64	<b>0.02</b>	0.57 (0.31 to 1.04)	0.07
History of recurrence	No	127 (30.1)	103 (24.4)	<b>Ref (1)</b>			
	Yes	99 (23.5)	93 (22)	1.16	0.45		
History of hypertension	No	122 (28.9)	41 (9.7)	<b>Ref (1)</b>			
	Yes	104 (24.6)	155 (36.7)	4.43	<b>&lt;0.0001</b>	4.59 (2.61 to 8.07)	<b>&lt;0.0001*</b>
History of DM	No	174 (41.2)	134 (31.8)	<b>Ref (1)</b>			
	Yes	52 (12.3)	62 (14.7)	1.55	<b>0.05</b>	0.63 (0.35 to 1.14)	0.13
History of heart diseases	No	201 (47.6)	139 (32.9)	<b>Ref (1)</b>			
	Yes	25 (5.9)	57 (13.5)	<b>3.30</b>	<b>&lt;0.0001</b>	1.94 (1.19 to 3.82)	<b>0.04*</b>
Level of disability according to mRS	No symptoms at all	47 (11.1)	12 (2.8)	<b>Ref (1)</b>			
	No significant disability	111 (26.3)	48 (11.4)	1.69	<b>0.15</b>	1.66 (0.73 to 3.81)	<b>0.23</b>
	Slight disability	52 (12.3)	70 (16.6)	5.27	<b>&lt;0.0001</b>	4.59 (1.94 to 10.83)	<b>0.001*</b>
	Moderate disability and above	16 (3.8)	66 (15.6)	16.16	<b>&lt;0.0001</b>	26.4 (8.61 to 80.92)	<b>&lt;0.0001*</b>
Physiotherapy utilisation	Yes	100 (23.7)	57 (13.5)	<b>Ref (1)</b>			
	No	126 (29.9)	139 (32.9)	1.94	<b>0.001</b>	2.85 (1.63 to 4.99)	<b>&lt;0.0001*</b>

Bold variables were significant at  $P < 0.05$ .

\*Indicates the variables were significant at  $p < 0.05$ , Ref=reference group (those least to have longer-term unmet supportive care needs were considered as a reference group). AOR, adjusted OR; COR, crude OR; DM, diabetes mellitus; mRS, modified Rankin Scale; SAH, Subarachnoid hemorrhage.

difference might be as a result of the medical and rehabilitation system differences of the two countries.

Needing advice on getting back to driving was one of the least reported unmet needs (26.1%) while seeking information on how to use public transportation again was one of the highly reported unmet needs (80.6%). Similar findings were reported in Europe regarding transport and travel concerns.<sup>21</sup> Adaptations or aids like a stair-lift, grab rails inside the home are reported by 53.1% of the study respondents in this study, whereas adaptations outside the home such as a ramp, rail, or wheelchair were reported by half of the respondents (50.2%).

On the other hand, a study conducted in Australia mentioned that mobility aids and home adaptations were provided for 54% and 31% of the patient's, respectively, after discharge from the hospital and this facilitated their ability to adapt to ongoing physical disabilities following their stroke. Mobility aids comprised wheelchairs, scooters, walking sticks and frames, which allowed physical functioning as well as independence.<sup>22</sup>

In our study, we found that sexuality needs were reported by 49.3% of the participants. Intimacy problems were mentioned as one of the most commonly reported emotional problems after stroke according to the study conducted in USA<sup>23</sup> and in Europe.<sup>10</sup> This figure was low and should be understood with attention because talking about sex is taboo or embarrassing in the culture of our setup so patients might not be honest about sexual relationship questions. Moreover, this might eventually make patients distinguish that sexuality is of little significance despite having certain sexual problems.

### Limitations of this study

The study was not without limitations, stroke survivors coming to the facility might have more comorbidities and thus report more unmet needs than stroke survivors in the community. Even though the sample size is adequate, generalisation is limited by the sampling method used. Dichotomising the outcome might have disproportionately affected those who have labelled as having 'no unmet needs'. Since qualitative data were not collected, a detailed understanding of the longer-term unmet needs among stroke survivors is limited. In addition, even though we conducted a pretest to assess the clarity of the LUNS tool a validation study was not conducted as the tool has never been used in Ethiopia. Acknowledging these potential limitations we hope that this finding can serve as baseline information for further research.

### CONCLUSIONS

We have found a significant proportion of adult stroke survivors having a longer-term unmet supportive care need. The factors associated with longer-term unmet supportive care needs were; having comorbidities, moderate and above level of disability according to the mRS score, and unable to use the physiotherapy service.

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### REFERENCES

- GBD. Disease and injury incidence and prevalence Collaborators. global, regional, and national incidence, prevalence, and years lived with disability for 354 diseases and injuries for 195 countries and territories, 1990–2017: a systematic analysis for the global burden of disease study 2017. *Lancet* 2018;390:1789–858.
- Strong K, Mathers C, Bonita R. Preventing stroke: saving lives around the world. *Lancet Neurol* 2007;6:182–7.
- Association S. *Together we can conquer stroke: stroke association strategy 2015 to 2018*, 2013: 1–23.
- Kelley AS, Morrison RS. Palliative care for the seriously ill. *N Engl J Med* 2015;373:747–55.
- World Health Organization Regional Office for Africa. Health situation analysis of the African region. *Atlas Afr Health Stat* 2012 <https://www.afro.who.int/publications/atlas-african-health-statistics-2012-health-situation-analysis-african-region>
- Walker R, Whiting D, Unwin N, et al. Stroke incidence in rural and urban Tanzania: a prospective, community-based study. *Lancet Neurol* 2010;9:786–92.
- Okoye EC, Awhen PA, Akosile CO, et al. Caregiver-proxy reliability of the Igbo-culture adapted Maleka stroke community reintegration measure: a validation study. *Top Stroke Rehabil* 2017;24:422–7.
- Sarfo FS, Akassi J, Kyem G, et al. Long-Term outcomes of stroke in a Ghanaian outpatient clinic. *J Stroke Cerebrovasc Dis* 2018;27:1090–9.



- 9 Sarfo FS, Adamu S, Awuah D, *et al.* Potential role of tele-rehabilitation to address barriers to implementation of physical therapy among West African stroke survivors: a cross-sectional survey. *J Neurol Sci* 2017;381:203–8.
- 10 Abrahamson V, Wilson PM. How unmet are unmet needs post-stroke? A policy analysis of the six-month review. *BMC Health Serv Res* 2019;19:480–9.
- 11 Center for disease control and prevention. *Epi info, a data base and statistics program for public health professionals*. Atlanta, Georgia, USA: Center for disease control and prevention, 2018.
- 12 Banks JL, Marotta CA. Outcomes validity and reliability of the modified Rankin scale: implications for stroke clinical trials: a literature review and synthesis. *Stroke* 2007;38:1091–6.
- 13 LoTS care LUNS study team. Validation of the longer-term unmet needs after stroke (LUNS) monitoring tool: a multicentre study. *Clin Rehabil* 2013;27:1020–8.
- 14 Murray CD, Harrison B. The meaning and experience of being a stroke survivor: an interpretative phenomenological analysis. *Disabil Rehabil* 2004;26:808–16.
- 15 Hotter B, Padberg I, Liebenau A, *et al.* Identifying unmet needs in long-term stroke care using in-depth assessment and the Post-Stroke Checklist - The Managing Aftercare for Stroke (MAS-I) study. *Eur Stroke J* 2018;3:237–45.
- 16 StataCorp. *Stata statistical software: release 14*. College Station, Texas, USA: StataCorp LLC, 2017.
- 17 David WH, Stanley L. *Applied logistic regression*. 2nd edn. Massachusetts, USA: Wiley series in probability and statistics, 2000: 95.
- 18 Deresse B, Shaweno D. Epidemiology and in-hospital outcome of stroke in South Ethiopia. *J Neurol Sci* 2015;355:138–42.
- 19 Benjamin EJ, Virani SS, Callaway CW, *et al.* Heart disease and stroke Statistics—2018 update: a report from the American heart association. *Circulation* 2018;137.
- 20 Lehnerer S, Hotter B, Padberg I, *et al.* Social work support and unmet social needs in life after stroke: a cross-sectional exploratory study. *BMC Neurol* 2019;19:1–10.
- 21 Chen T, Zhang B, Deng Y, *et al.* Long-Term unmet needs after stroke: systematic review of evidence from survey studies. *BMJ Open* 2019;9:e028137.
- 22 Murgo M, Cavanagh K, Latham S. Health related quality of life and support needs for sub-arachnoid haemorrhage survivors in New South Wales Australia. *Aust Crit Care* 2016;29:146–50.
- 23 McCurley JL, Funes CJ, Zale EL, *et al.* Preventing chronic emotional distress in stroke survivors and their informal caregivers. *Neurocrit Care* 2019;30:581–9.