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Factors associated with the Long Term Unmet Supportive Care Needs of Stroke Survivors in Ethiopia: A multi-center cross-sectional study

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4 **Original research**
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9 **Factors associated with the Long Term Unmet Supportive Care Needs of**
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11 **Stroke Survivors in Ethiopia: A multi-center cross sectional study**
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23 Abstract

24 **Objectives:** To assess the magnitude of the Long-Term Unmet Supportive Care Needs and
25 associated factors among adult Stroke Survivors.

26 **Design:** An institutional-based multi-center cross-sectional study.

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

28 **Participants:** Adult Stroke Survivors (aged ≥ 18 years, n=422), diagnosed with a stroke at least
29 six months before the study period and who started regular follow-up at the Neurology
30 Outpatient clinics in Addis Ababa, Ethiopia.

31 **Main outcome measures:** Self-reported long-term supportive care needs.

32 **Results:** Two hundred twenty-six (53.6%) stroke survivors had long-term unmet supportive care
33 needs, and 196 (46.4%) survivors had no long-term unmet supportive care needs. Information
34 need about stroke reported by 416 (98.6%), and how to travel on public transportation reported
35 by 340 (80.6%) survivors were the most frequently reported unmet needs. Stroke survivors long
36 term unmet supportive care needs were significantly associated with being hypertensive with
37 (AOR= 4.59; 95% CI 2.61-8.07), having heart disease with (AOR=1.94; 95% CI 1.19-3.82),
38 moderate and above level of disability according to the modified Rankin Scale score with
39 (AOR=26.4; 95% CI 8.61-80.92), and unable to use the physiotherapy service with (AOR= 2.85;
40 95% CI of 1.63-4.99).

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

46 **Strengths and limitations of this study**

47 ✚ This was the first local study using the standardized instrument for measuring stroke patients'
48 longer-term unmet needs and this can serve as baseline information for further research in
49 Ethiopia and Sub-Saharan Africa.

50 ✚ The previous studies were mainly focused on the descriptive summary of the unmet needs,
51 but this study tried to identify the factors associated with stroke survivor's long-term unmet
52 needs.

53 ✚ Stroke survivors coming to the facility might have more comorbidities and thus report more
54 unmet needs than stroke survivors in the community. Even though the sample size is
55 adequate, generalization is limited by the sampling method used.

56 ✚ Since qualitative data was not collected, a detailed understanding of the long-term unmet
57 needs among stroke survivors is limited.

58 **Introduction**

59 Globally, stroke is the second leading cause of death following ischemic heart disease, being
60 responsible for 8.76 million deaths, and taking lives every five seconds. Stroke is the second
61 most common cause of adult disability (4.6%) of the global Disability Adjusted Life Years
62 (DALYs).¹ Without significant interventions, the global stroke mortality is estimated to rise to
63 7.8 million deaths per year by the end of 2030.² The global economic cost of adult stroke is more
64 than 25 billion dollars per year.³

65 Supportive care is defined as, rendering essential services that satisfy stroke patients' physical,
66 psychological, social, informational, and spiritual needs over the entire illness trajectory.

67 Supportive care is an essential buffering component of stroke survivors that helps to regain

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3 68 emotional stability, social adjustment, cognitive function, body image, future perspective, and
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5 69 physical recovery.⁴
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8 70 In Sub-Saharan Africa (SSA), stroke primarily affects the young and productive segment of the
9
10 71 population.^{5,6} The development of appropriate service provision is limited by the lack of
11
12 72 vigorous estimates of long-term outcomes after stroke and the prevalence of stroke survivors in
13
14 73 SSA was reported to be 14.6/1,000 people.⁷ High burden of uncontrolled vascular risk factors
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16 74 due to low screening and treatment modalities, uncoordinated, and fragmentary acute stroke care,
17
18 75 and limited rehabilitation services were described as factors associated with poor prognosis after
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20 76 Stroke.^{5,7} The increase in the magnitude of Stroke, thus calls the urge to identify their unmet
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22 77 needs to accelerate their recovery.⁸
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27 78 In Sub-Saharan Africa, the physiotherapists to population ratio range from 0.1/100,000 people in
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29 79 Ethiopia to 6.7/100,000 people in South Africa.⁵ There is a high mismatch in the long-term
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31 80 stroke rehabilitation care need and delivery. Long-term supportive care service delivery should
32
33 81 be patient-oriented and designed compatible with the local situation.⁹ Therefore, assessing the
34
35 82 needs of stroke survivors is essential to improve stroke survivors' quality of life.^{9, 10} Even though
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37 83 the unmet need for supportive care for cancer and chronic kidney failure patients is documented,
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39 84 much attention was not given to the supportive care services among stroke survivors.⁴
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44 85 To the best of our knowledge, we did not get studies conducted in Sub-Saharan Africa, including
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46 86 in Ethiopia, which determines the long-term unmet supportive care needs, and associated factors
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48 87 among adult stroke survivors. This study was intended to assess the magnitude of the long-term
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50 88 unmet supportive care needs, and associated factors among adult stroke survivors in Tikur
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52 89 Anbessa Specialized Hospital and Saint Paul's Hospital Millennium Medical College, Addis
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54 90 Ababa, Ethiopia.
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91 **Methods and Materials**

92 The study was conducted in Tikur Anbessa Specialized Hospital (TASH) and Saint Paul's
93 Hospital Millennium Medical College (SPHMMC) in Addis Ababa, the capital city of Ethiopia.
94 TASH is the first largest government-owned hospital serving as a teaching hospital of Addis
95 Ababa University and a major referral center from all over the country. TASH provides service
96 to different Neurologic cases at the Neurology Outpatient Department (OPD) twice a week and
97 allocated one additional day to treat stroke survivors in the OPD. SPHMMC is the second-largest
98 hospital in Ethiopia following TASH. It treats neurologic cases four days a week in the
99 Neurology OPD. The study was conducted from March 1, 2020, to May 31, 2020.

100 **Study design:** An institutional-based multi-center cross-sectional study was conducted.

101 **Populations:** Those adult stroke survivors (aged ≥ 18 years) who were diagnosed with stroke at
102 least 6-months before the study period and who started follow up at the Neurology Outpatient
103 Departments of TASH and SPHMMC were considered as the study population. Those stroke
104 survivors who were not able to represent themselves, who didn't have anyone to represent them
105 as a caregiver were excluded from the study.

106 **Sample size determination and sampling technique**

107 The sample size was determined by applying a single population proportion formula using Epi
108 Info version 7.2.4.0 software¹¹, with the assumptions of a 95% level of confidence, a 5% margin
109 of error. Since we couldn't find any previous studies conducted in Africa to determine the long-
110 term unmet supportive care needs among adult stroke survivors, the sample size was calculated
111 by taking the largest sample size to detect a statistically significant difference. Accordingly, the
112 percent of stroke survivors who have long-term unmet supportive care needs 50%, with these

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3 113 assumptions the sample size was 384, and after adding a 10% non-response rate the final sample
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5 114 size was 422.
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7 115 **Sampling procedure**

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10 116 A convenient sampling technique was used to select the study participants, accordingly, all adult
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12 117 stroke survivors who were available at the Neurology OPDs of TASH and SPHMMC during the
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15 118 study period who meet the inclusion criteria were included in the study.
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17 119 **Data collection instrument**

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19 120 A pre-tested structured interviewer-administered questionnaire, which contains the socio-
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21 121 demographic, clinical, neurological factors, and the Long Term Unmet Supportive Care Needs
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23 122 (LUNs) questions, was used to collect the data. The interviewer-administered questionnaire was
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26 123 prepared in English then translated into the local language (Amharic) and re-translated back to
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28 124 English to maintain its consistency. The level of disability of the stroke survivors was measured
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31 125 by using the Modified Rankin Scale (mRS).¹²
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34 126 The LUNs is a 22-item standardized instrument for measuring stroke patients' longer-term unmet
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36 127 needs.¹³ The 22 variables that were included in the LUNS tool were combined into one by
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38 128 calculating the mean, the mean of these variables was further dichotomized by calculating its
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41 129 population mean as having no unmet need and having an unmet need. If a patient-reported an
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43 130 unmet need that was above the population mean, it is considered as having an unmet need. On
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45 131 the other hand, if a patient reports unmet needs below the mean value it was considered as
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47 132 having no unmet need.
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49 133 **Operational definitions**

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51
52 134 Stroke survivor: is a person who has had a stroke attack previously and is not currently receiving
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54 135 acute comma care.¹⁴ Long Term Supportive Care Needs: These includes physical relationships,
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3 136 managing money, accessible holidays, pain, driving, memory, information, employment,
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5 137 benefits, daily occupations, bladder control, mood, adaptations outside, diet, home help, moving
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8 138 house, transportation, adaptations inside, falling, mobility, blood pressure.¹⁵
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10 139 Needs: Issues and/or actions that are deemed necessary by the survivor to manage his/her
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12 140 wellbeing and best quality of care. An unmet need: a problem that was not being addressed or
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14 141 one that was being addressed, but insufficiently. Long-term unmet need: unmet needs that exist
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16 142 at least after 6-month post-stroke.¹⁵
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19 143 **Data processing, management, and analysis**

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21 144 The collected data was coded and checked for its consistency and completeness up to the end of
22
23 145 each data collection period. Before the analysis, the whole data were cleaned and 20% of the data
24
25 146 were double-entered randomly to check for data entry errors, and Epi Info version 7.2.4.0
26
27 147 software¹¹ was used for data entry. The entered data were exported to STATA version 14.0 for
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29 148 windows.¹⁶ Descriptive statistics were presented in medians with interquartile range for
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31 149 numerical variables and categorical variables were presented using frequency and percentages.
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36 150 The bivariate analysis was done to check the existence of crude association and to select
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38 151 candidate variables, those variables which are clinically important and having ($P < 0.25$) were
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40 152 included in the final model.¹⁷ Confounding was checked, and percentage change in the regression
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42 153 coefficients (β) less than 20% reveals an absence of confounder. Interaction for the main effect
43
44 154 model was also be checked and partial likelihood ratio test result with $p\text{-value} > 0.05$ and
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46 155 Variance inflation factor less than 10 indicating the non-existence of multi-collinearity among
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48 156 the independent variables.
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53 157 The multivariable binary logistic regression model was used to identify the independent factors
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55 158 associated with long-term unmet supportive care needs. The summary measures of estimated
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159 crude (COR) and adjusted odds ratios (AOR) with 95% confidence interval were presented and
 160 P-value less than 0.05 was used to declare statistical significance and goodness of fit of the
 161 model was assessed by using Hosmer and Lemeshow goodness of fit test. Finally, the results
 162 were presented in statements, tables, and figures.

163 Results

164 Sociodemographic characteristics

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

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

Variables	Categories	Frequency	Percent (%)
Age, median (25 th -75 th), 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 ^a	96	22.9
	Unemployed	39	9.3
	Housewife	15	3.6
	Others ^w	19	4.5
Monthly income (In USD) (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)	≤ 5 members	276	67.3
	> 5 members	134	32.7

172 **Abbreviations:** ^aNGO: Non-governmental organization. USD: United States Dollar. #**others:** Afar,
 173 Southern Nations, nationalities and peoples regional state. Others^w: Student, and daily laborer.

174 **Clinical characteristics of participants**

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

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

Patient profile	Categories	Frequency	Percentage (%)
Stroke type	Ischemic	360	85.3
	Hemorrhagic	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

184 **Abbreviation:** [‡]mRS: Modified Rankin Scale

185 **Physiotherapy service utilization**

186 One hundred fifty-seven (37.2%) stroke survivors utilized physiotherapy services, and 265
187 (62.8%) of the survivors do not utilize physiotherapy services (Figure 1). Among those who
188 utilized physiotherapy service, 13(8.3%) were receiving physiotherapy every day excluding
189 weekends and holidays, meanwhile, 56 (35.7%) of the survivors utilized 2-3 times per week for
190 30-45 minutes. On the other hand, 61 (38.8%) of the survivors utilized physiotherapy less than
191 two times a week, and 27 (17.2%) of the survivors utilized physiotherapy irregularly. Financial
192 problems, lack of transport service, and unsatisfied with the physiotherapy service were the
193 reasons for not utilizing physiotherapy service reported by 100 (38.2%), 54 (20.6%), and 108
194 (41.2%) survivors respectively.

195 **The magnitude of unmet supportive care needs**

196 All stroke survivors reported at least one unmet need, 416 (98.6%) survivors stated that they
197 need more information about their stroke, why it happened, and how to avoid having another
198 one. The next two common unmet needs were, seeking advice on how to use public
199 transportation reported by, 340 (80.6%) and seeking advice on modifying their diet reported by
200 335 (79.4%) (Table 3). Two hundred twenty-six (53.6%) stroke survivors had long-term unmet
201 supportive care needs (LUNs), and 196 (46.4%) survivors had no long-term unmet supportive
202 care needs (Figure 2).

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

Long Term Unmet Supportive Care Needs (LUNs) questions	Patient Response	
	Yes	No
	Frequency (%)	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 traveling 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)

209 **Factors associated with Long Term Unmet needs**

210 In the final multivariable binary logistic regression model, after controlling the effect of other
 211 confounders, hypertensive stroke survivors are four times more likely to have Long Term Unmet
 212 Supportive Care Needs than non-hypertensive survivors with (AOR= 4.59; 95% CI 2.61-8.07).

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3 213 Similarly, those stroke survivors who have heart disease are two times more likely to have long-
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10 216 Those stroke survivors who have a moderate and above level of disability according to the
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13 217 Modified Rankin Scale (mRS) score have a very significant long-term unmet supportive care
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15 218 needs than those who have no symptoms at all with (AOR=26.4; 95% CI 8.61-80.92). Stroke
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18 219 survivors who utilized physiotherapy services are three times more likely to have long-term
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20 220 unmet supportive care needs than those who do not use physiotherapy services (AOR= 2.85; 95%
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22 221 CI 1.63-4.99) (Table 4).

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229 Table 4: Factors associated with long term unmet supportive care needs among adult stroke survivors, Addis Ababa, Ethiopia, 2020
 230 (n=422)

Patient profile	Categories	Long 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)				Ref (1)
	45-54	59 (14)	40 (9.5)	0.87	0.62	0.59 (0.27,1.26)	0.17
	55-64	61 (14.5)	57 (13.5)	1.20	0.49	0.99 (0.47,2.07)	0.98
	65-74	32 (7.6)	23 (5.5)	0.92	0.81	0.38 (0.15,1.97)	0.17
	≥ 75	11 (2.6)	27 (6.3)	3.16	0.00	1.72 (0.62,4.76)	0.29
Gender	Male	129 (30.6)	114 (27)				Ref (1)
	Female	97 (23)	82 (19.4)	0.96	0.82		
Residence	Urban	193 (45.7)	145 (34.4)				Ref (1)
	Rural	33 (7.8)	51 (12.1)	2.06	0.00	2.54 (0.93,6.89)	0.07
Region	Addis Ababa	171 (40.5)	136 (32.2)				Ref (1)
	Out of Addis Ababa	55 (13)	60 (14.3)	1.37	0.15	0.96 (0.38,2.40)	0.93
Marital status	Married	149 (35.3)	133 (31.5)				Ref (1)
	Never married	20 (4.7)	30 (7.1)	1.68	0.1	1.56 (0.68,3.59)	0.29
	Divorced	12 (2.8)	20 (4.7)	1.87	0.1	0.73 (0.26,2.05)	0.09
	Common law	45 (10.7)	13 (3.1)	0.32	0.00	0.50 (0.23,1.11)	0.55
Educational level	Able to read, write and above	204 (48.3)	178 (42.2)				Ref (1)
	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)				Ref (1)
	Non-government employee	159 (38)	122 (29.1)	0.68	0.07	0.69 (0.31,1.04)	0.2
Monthly income (In USD) (n=419)	> 120	71 (17)	57 (13.6)				Ref (1)
	≤ 120	153 (36.5)	138 (32.9)	1.12	0.59		
Family size (n=410)	≤ 5 members	141 (34.4)	135 (32.9)				Ref (1)
	> 5 members	73 (17.8)	61 (14.9)	0.87	0.52		
Stroke type	Ischemic	196 (46.5)	164 (38.9)				Ref (1)

	Hemorrhagic	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)				Ref (1)
	< 12 months	72 (17.1)	85 (20.2)	1.64	0.02	0.57 (0.31,1.04)	0.07
History of recurrence	No	127 (30.1)	103 (24.4)				Ref (1)
	Yes	99 (23.5)	93 (22)	1.16	0.45		
History of hypertension	No	122 (28.9)	41 (9.7)				Ref (1)
	Yes	104 (24.6)	155 (36.7)	4.43	<0.0001	4.59 (2.61,8.07)	<0.0001**
History of DM	No	174 (41.2)	134 (31.8)				Ref (1)
	Yes	52 (12.3)	62 (14.7)	1.55	0.05	0.63 (0.35,1.14)	0.13
History of heart diseases	No	201 (47.6)	139 (32.9)				Ref (1)
	Yes	25 (5.9)	57 (13.5)	3.30	<0.0001	1.94 (1.19,3.82)	0.04**
Level of disability according to mRS [‡]	No symptoms at all	47 (11.1)	12 (2.8)				Ref (1)
	No significant disability	111 (26.3)	48 (11.4)	1.69	0.15	1.66 (0.73,3.81)	0.23
	Slight disability	52 (12.3)	70 (16.6)	5.27	<0.0001	4.59 (1.94,10.83)	0.001**
	Moderate disability and above	16 (3.8)	66 (15.6)	16.16	<0.0001	26.4 (8.61,80.92)	<0.0001**
Physiotherapy Utilization	Yes	100 (23.7)	57 (13.5)				Ref (1)
	No	126 (29.9)	139 (32.9)	1.94	0.001	2.85 (1.63,4.99)	<0.0001**

231 Abbreviations: AOR= Adjusted odds ratio, COR= Crude odds ratio, CI= confidence interval, DM: Diabetes Mellitus, [‡]mRS: Modified Rankin

232 Scale, ** indicates the variables were significant at P<0.05, Ref= reference group (those least to have long term unmet supportive care needs were

233 considered as a reference group).

234

235 Discussion

236 Background

237 This study assessed the magnitude of the long-term unmet supportive care needs and its
238 associated factors among adult stroke survivors in Tikur Anbessa Specialized Hospital and Saint
239 Paul's Hospital Millennium Medical College. We found that being hypertensive, having heart
240 disease, moderate and above level of disability according to the Modified Rankin Scale score,
241 unable to use the physiotherapy service were the factors associated with the higher experience of
242 the Long Term Unmet Supportive Care Needs.

243 Socio-demographic Characteristics

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

252 Clinical Characteristics

253 History of hypertension was reported by 61 % of stroke survivors. Similarly, another study
254 conducted in Addis Ababa Ethiopia mentioned that hypertension occurred in 65% of the total
255 study participants irrespective of their stroke type. In this study, the history of heart disease was
256 significantly associated with long-term unmet supportive care needs, this finding goes in line

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3 257 with a study conducted in Europe by which patients who had comorbidities reported more unmet
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5 258 needs than the others.¹⁹
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8 259 The level of disability according to the Modified Rankin Scale was significantly associated with
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10 260 long-term unmet needs. This finding was consistent with a study conducted in Germany by
11
12 261 which the level of disability of stroke survivors was significantly associated with unmet
13
14 262 psychosocial supportive care needs.²⁰
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17 263 Physiotherapy utilization was reported by 37.2 % of the participants in this study. Similarly, a
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19 264 study which was conducted in West Africa stated that the physiotherapy utilization of stroke
20
21 265 survivors is low.⁹ In this study, not being able to afford the services provided, a long distance
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23 266 from home to the physiotherapy utilization centers, transportation-related issues, and
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25 267 unsatisfactory services were identified as reasons for not using physiotherapy.
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27

28 268 **The magnitude of unmet needs**

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30 269 The magnitude of unmet supportive care needs in this study ranges from 26.1% (Driving needs)
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32 270 to 98.6% (Information needs). Similarly, a study conducted in Germany found that 54% of
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34 271 survivors reported they need more information about the cause of their stroke and prevention of
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36 272 recurrence.²⁰ In our study 54% reported needs related to pain management (they have constant
37
38 273 pain and nothing seems to ease it). On the other hand, a study conducted in England stated that
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40 274 only 39.5% of stroke survivors reported unmet needs regarding pain.¹⁰ This difference might be
41
42 275 as a result of the medical and rehabilitation system differences of the two countries.
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47 276 Needing advice on getting back to driving was one of the least reported unmet needs (26.1%)
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49 277 while seeking information on how to use public transportation again was one of the highly
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51 278 reported unmet needs (80.6%). Similar findings were reported in Europe regarding transport and
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53 279 travel concerns.²¹ Adaptations or aids like a stairlift, grab rails inside the home are reported by
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280 53.1% of the study respondents in this study, whereas adaptations outside the home such as a
281 ramp, rail, or wheelchair were reported by half of the respondents (50.2%).

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

287 In our study, we found that sexuality needs were reported by 49.3% of the participants. Intimacy
288 problems are mentioned as one of the most commonly reported emotional problems after stroke
289 according to the study conducted in USA²³ and a study conducted in Europe.¹⁰ This figure was
290 low and should be understood with attention because talking about sex is taboo or embarrassing
291 in the culture of our setup so patients might not be honest about sexual relationship questions.
292 Moreover, this might eventually make patients distinguish that sexuality is of little significance
293 despite having certain sexual problems.

294 **Limitations of this study**

295 The study was not without limitations, stroke survivors coming to the facility might have more
296 comorbidities and thus report more unmet needs than stroke survivors in the community. Even
297 though the sample size is adequate, generalization is limited by the sampling method used. Since
298 qualitative data was not collected, a detailed understanding of the long term unmet needs among
299 stroke survivors is limited. Acknowledging these potential limitations we hope that this finding
300 can serve as baseline information for further research.

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1
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3 303 **Conclusions**
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5 304 We have found a significant proportion of adult stroke survivors having a long-term unmet
6
7 305 supportive care need. The factors associated with long-term unmet supportive care needs were;
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10 306 having comorbidities, moderate and above level of disability according to the modified Rankin
11
12 307 Scale score, and unable to use the physiotherapy service.

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14
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18
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24 312 **Competing interests:** None declared.

25
26 313 **Contributors:** EGT: project inception, management, and clinical input. MG, YMY: project
27
28 314 inception, questionnaire design. SG and ZHG conducted the statistical analysis and interpreted
29
30 315 the findings. All contributed to this manuscript and approved the final draft.

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33 316 **Patient and public involvement:** Patients and/or the public were not involved in the design, or
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35 317 conduct, or reporting, or dissemination plans of this research.

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38 318 **Patient consent for publication:** Not required.

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40 319 **Ethics approval:** The study received approval from the institutional review board of the School
41
42 320 of Public Health, Addis Ababa University (Ref: SPH/005/2020).

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45 321 **Data availability statement:** The datasets generated and analyzed during the current study are
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47 322 available from the corresponding author on a reasonable request.

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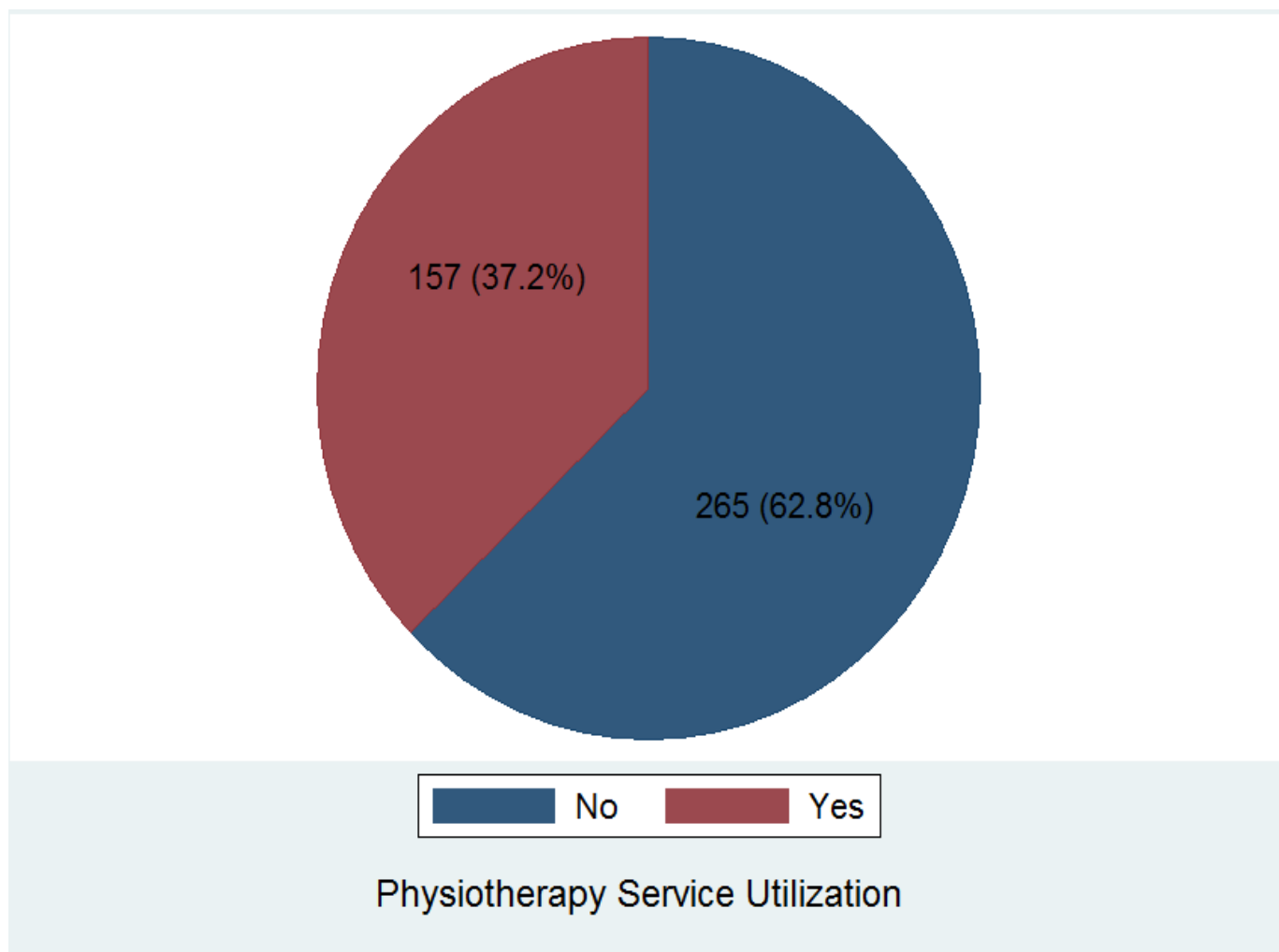
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3 **388 Figure legends**
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5 389 Figure 1: Magnitude of Physiotherapy service utilization among adult stroke survivors receiving
6 routine follow-up services Addis Ababa, Ethiopia, 2020 (n=422).
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10 391 Figure 2: Magnitude of Long Term Unmet Supportive Care Needs among adult stroke survivors
11 receiving routine follow-up services Addis Ababa, Ethiopia, 2020 (n=422).
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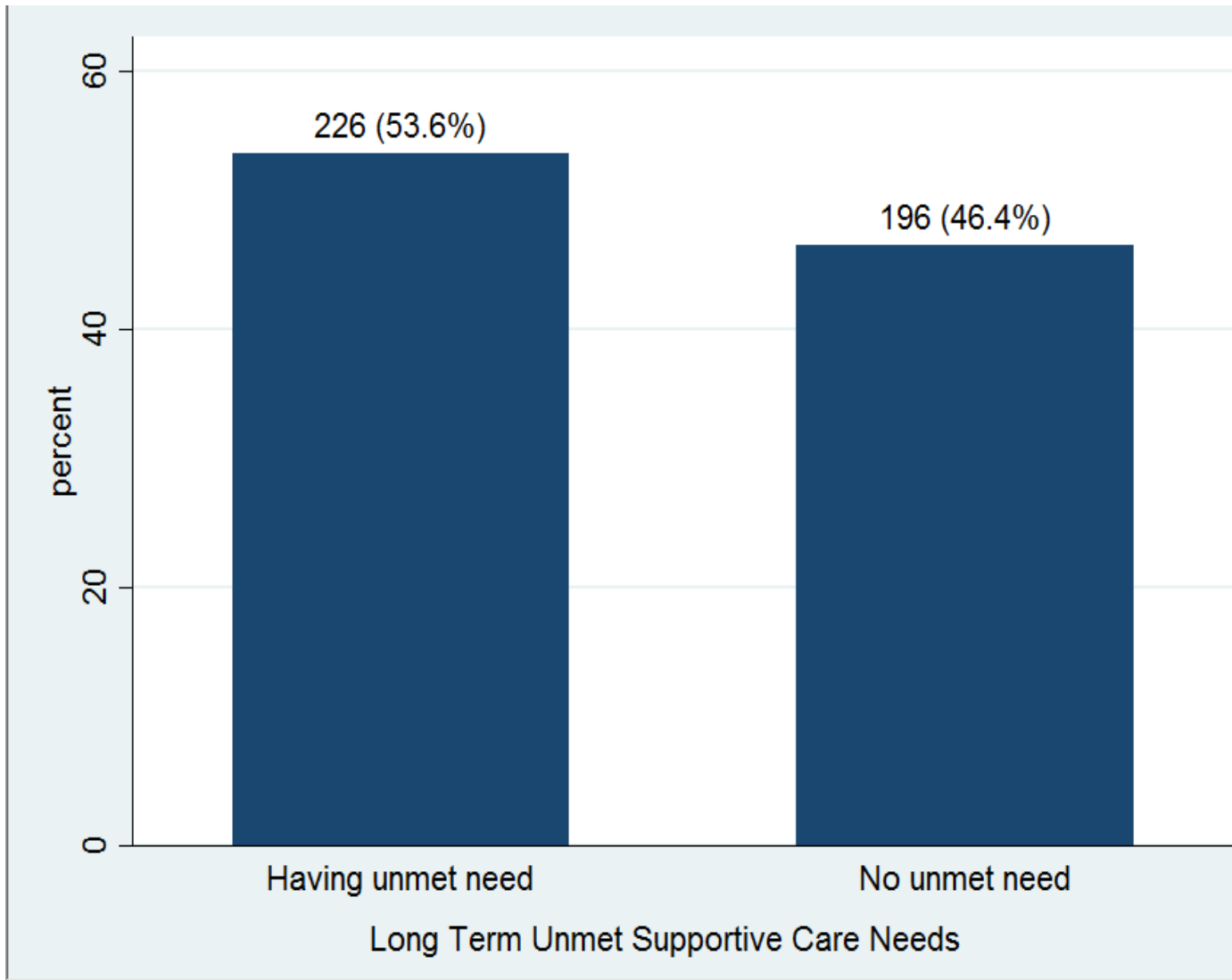
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Physiotherapy Service Utilization

View only

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STROBE Statement—Checklist of items that should be included in reports of *cross-sectional studies*

	Item No	Recommendation
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract (b) Provide in the abstract an informative and balanced summary of what was done and what was found
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported
Objectives	3	State specific objectives, including any prespecified hypotheses
Methods		
Study design	4	Present key elements of study design early in the paper
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group
Bias	9	Describe any efforts to address potential sources of bias
Study size	10	Explain how the study size was arrived at
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding (b) Describe any methods used to examine subgroups and interactions (c) Explain how missing data were addressed (d) If applicable, describe analytical methods taking account of sampling strategy (e) Describe any sensitivity analyses
Results		
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed (b) Give reasons for non-participation at each stage (c) Consider use of a flow diagram
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders (b) Indicate number of participants with missing data for each variable of interest
Outcome data	15*	Report numbers of outcome events or summary measures
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included (b) Report category boundaries when continuous variables were categorized (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses

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Discussion		
Key results	18	Summarise key results with reference to study objectives
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence
Generalisability	21	Discuss the generalisability (external validity) of the study results
Other information		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at www.strobe-statement.org.

BMJ Open

Factors associated with the Longer-Term Unmet Supportive Care Needs of Stroke Survivors in Ethiopia: A multi-center cross-sectional study

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Primary Subject Heading:	Neurology
Secondary Subject Heading:	Neurology, Public health, Epidemiology
Keywords:	STROKE MEDICINE, STATISTICS & RESEARCH METHODS, PUBLIC HEALTH, Adult palliative care < PALLIATIVE CARE, Stroke < NEUROLOGY

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9 3 **Factors associated with the Longer Term Unmet Supportive Care Needs of**
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12 4 **Stroke Survivors in Ethiopia: A multi-center cross sectional study**
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18 7 Edna Gebremichael Tamrat^{1*}, Zenawi Hagos Gufue³, Sefonias Getachew¹, Yared Mamushet
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23 Abstract

24 **Objectives:** To assess the magnitude of the Longer-Term Unmet Supportive Care Needs and
25 associated factors among adult Stroke Survivors.

26 **Design:** An institutional-based multi-center cross-sectional study.

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

28 **Participants:** Adult Stroke Survivors (aged ≥ 18 years, n=422), diagnosed with a stroke at least
29 six months before the study period and who started regular follow-up at the Neurology
30 Outpatient clinics in Addis Ababa, Ethiopia.

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

32 **Results:** Two hundred twenty-six (53.6%) stroke survivors had longer-term unmet supportive
33 care needs, and 196 (46.4%) survivors had no longer-term unmet supportive care needs.
34 Information need about stroke reported by 416 (98.6%), and how to travel on public
35 transportation reported by 340 (80.6%) survivors were the most frequently reported unmet needs.
36 Stroke survivors longer term unmet supportive care needs were significantly associated with
37 being hypertensive with (AOR= 4.59; 95% CI 2.61-8.07), having heart disease with (AOR=1.94;
38 95% CI 1.19-3.82), moderate and above level of disability according to the modified Rankin
39 Scale score with (AOR=26.4; 95% CI 8.61-80.92), and unable to use the physiotherapy service
40 with (AOR= 2.85; 95% CI of 1.63-4.99).

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

46 **Strengths and limitations of this study**

47 ✚ This was the first local study using the standardized instrument for measuring stroke patients'
48 longer-term unmet needs and this can serve as baseline information for further research in
49 Ethiopia and Sub-Saharan Africa.

50 ✚ The previous studies were mainly focused on the descriptive summary of the unmet needs,
51 but this study tried to identify the factors associated with stroke survivor's longer-term unmet
52 needs.

53 ✚ Stroke survivors coming to the facility might have more comorbidities and thus report more
54 unmet needs than stroke survivors in the community. Even though the sample size is
55 adequate, generalization is limited by the sampling method used.

56 ✚ Since qualitative data was not collected, a detailed understanding of the longer-term unmet
57 needs among stroke survivors is limited.

58 **Introduction**

59 Globally, stroke is the second leading cause of death following ischemic heart disease, being
60 responsible for 8.76 million deaths, and taking lives every five seconds. Stroke is the second
61 most common cause of adult disability (4.6%) of the global Disability Adjusted Life Years
62 (DALYs).¹ Without significant interventions, the global stroke mortality is estimated to rise to
63 7.8 million deaths per year by the end of 2030.² The global economic cost of adult stroke is more
64 than 25 billion dollars per year.³

65 Supportive care is defined as, rendering essential services that satisfy stroke patients' physical,
66 psychological, social, informational, and spiritual needs over the entire illness trajectory.

67 Supportive care is an essential buffering component of stroke survivors that helps to regain

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3 68 emotional stability, social adjustment, cognitive function, body image, future perspective, and
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5 69 physical recovery.⁴
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8 70 In Sub-Saharan Africa (SSA), stroke primarily affects the young and productive segment of the
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10 71 population.^{5,6} The development of appropriate service provision is limited by the lack of
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12 72 vigorous estimates of longer-term outcomes after stroke and the prevalence of stroke survivors in
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14 73 SSA was reported to be 14.6/1,000 people.⁷ High burden of uncontrolled vascular risk factors
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16 74 due to low screening and treatment modalities, uncoordinated, and fragmentary acute stroke care,
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18 75 and limited rehabilitation services were described as factors associated with poor prognosis after
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20 76 Stroke.^{5,7} The increase in the magnitude of Stroke, thus calls the urge to identify their unmet
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22 77 needs to accelerate their recovery.⁸
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27 78 In Sub-Saharan Africa, the physiotherapists to population ratio range from 0.1/100,000 people in
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29 79 Ethiopia to 6.7/100,000 people in South Africa.⁵ There is a high mismatch in the longer-term
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31 80 stroke rehabilitation care need and delivery. Longer-term supportive care service delivery should
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33 81 be patient-oriented and designed compatible with the local situation.⁹ Therefore, assessing the
34
35 82 needs of stroke survivors is essential to improve stroke survivors' quality of life.^{9, 10} Even though
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37 83 the unmet need for supportive care for cancer and chronic kidney failure patients is documented,
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39 84 much attention was not given to the supportive care services among stroke survivors.⁴
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44 85 To the best of our knowledge, we did not get studies conducted in Sub-Saharan Africa, including
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46 86 in Ethiopia, which determines the longer-term unmet supportive care needs, and associated
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48 87 factors among adult stroke survivors. This study intended to assess the magnitude of the longer-
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50 88 term unmet supportive care needs, and associated factors among adult stroke survivors in Tikur
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52 89 Anbessa Specialized Hospital and Saint Paul's Hospital Millennium Medical College, Addis
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54 90 Ababa, Ethiopia.
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91 **Methods and Materials**

92 The study was conducted in Tikur Anbessa Specialized Hospital (TASH) and Saint Paul's
93 Hospital Millennium Medical College (SPHMMC) in Addis Ababa, the capital city of Ethiopia.
94 TASH is the first largest government-owned hospital serving as a teaching hospital of Addis
95 Ababa University and a major referral center from all over the country. TASH provides service
96 to different Neurologic cases at the Neurology Outpatient Department (OPD) twice a week and
97 allocated one additional day to treat stroke survivors in the OPD. SPHMMC is the second-largest
98 hospital in Ethiopia following TASH. It treats neurologic cases four days a week in the
99 Neurology OPD. The study was conducted from March 1, 2020, to May 31, 2020.

100 **Study design:** An institutional-based multi-center cross-sectional study was conducted.

101 **Participants:** Those adult stroke survivors (aged ≥ 18 years) who were diagnosed with stroke at
102 least 6-months before the study period and who started follow up at the Neurology Outpatient
103 Departments of TASH and SPHMMC were considered as the study population. Those stroke
104 survivors who were not able to represent themselves, who didn't have anyone to represent them
105 as a caregiver were excluded from the study.

106 **Sample size determination and sampling technique**

107 The sample size was determined by applying a single population proportion formula using Epi
108 Info version 7.2.4.0 software¹¹, with the assumptions of a 95% level of confidence, a 5% margin
109 of error. Since we couldn't find any previous studies conducted in Africa to determine the
110 longer-term unmet supportive care needs among adult stroke survivors, the sample size was
111 calculated by taking the largest sample size to detect a statistically significant difference.
112 Accordingly, the percent of stroke survivors who have long-term unmet supportive care needs

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3 113 50%, with these assumptions the sample size was 384, and after adding a 10% non-response rate
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5 114 the final sample size was 422.

6 7 8 115 **Sampling procedure**

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10 116 A convenience sampling technique was used to select the study participants, accordingly, all
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12 117 adult stroke survivors who were available at the Neurology OPDs of TASH and SPHMMC
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15 118 during the study period who meet the inclusion criteria were included in the study.

16 17 119 **Data collection instrument**

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19 120 A pre-tested structured interviewer-administered questionnaire, which contains the socio-
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21 121 demographic, clinical, neurological factors, and the Longer Term Unmet Supportive Care Needs
22
23 122 (LUNs) questions, was used to collect the data. The interviewer-administered questionnaire was
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25
26 123 prepared in English then translated into the local language (Amharic) and re-translated back to
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28 124 English to maintain its consistency. The level of disability of the stroke survivors was measured
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31 125 by using the Modified Rankin Scale (mRS).¹²

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34 126 The LUNs is a 22-item standardized instrument for measuring stroke patients' longer-term unmet
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36 127 needs.¹³ The 22 variables that were included in the LUNs tool were combined into one by
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38 128 calculating the mean, the mean of these variables was further dichotomized by calculating its
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41 129 population mean as having no unmet need and having an unmet need. If a patient-reported an
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43 130 unmet need that was above the population mean, it is considered as having an unmet need. On
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45 131 the other hand, if a patient reports unmet needs below the mean value it was considered as
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48 132 having no unmet need.

49 50 133 **Operational definitions**

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52 134 Stroke survivor: is a person who has had a stroke attack previously and is not currently receiving
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54 135 acute comma care or receiving an inpatient treatment in a hospital setting.¹⁴ Longer Term

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3 136 Supportive Care Needs: These includes physical relationships, managing money, accessible
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5 137 holidays, pain, driving, memory, information, employment, benefits, daily occupations, bladder
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7 138 control, mood, adaptations outside, diet, home help, moving house, transportation, adaptations
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10 139 inside, falling, mobility, blood pressure.¹⁵

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12 140 Needs: Issues and/or actions that are deemed necessary by the survivor to manage his/her
13
14 141 wellbeing and best quality of care. An unmet need: a problem that was not being addressed or
15
16 142 one that was being addressed, but insufficiently. Longer-term unmet need: unmet needs that exist
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18 143 at least after 6-month post-stroke.¹⁵

19 20 21 144 **Data processing, management, and analysis**

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24 145 The collected data was coded and checked for its consistency and completeness up to the end of
25
26 146 each data collection period. Before the analysis, the whole data were cleaned and 20% of the data
27
28 147 were double-entered randomly to check for data entry errors, and Epi Info version 7.2.4.0
29
30 148 software¹¹ was used for data entry. The entered data were exported to STATA version 14.0 for
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32 149 windows.¹⁶ Descriptive statistics were presented in medians with interquartile range for
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34 150 numerical variables and categorical variables were presented using frequency and percentages.

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38 151 The bivariate analysis was done to check the existence of crude association and to select
39
40 152 candidate variables, those variables which are clinically important and having ($P < 0.25$) were
41
42 153 included in the final model.¹⁷ Confounding was checked, and percentage change in the regression
43
44 154 coefficients (β) less than 20% reveals an absence of confounder. Interaction for the main effect
45
46 155 model was also be checked and partial likelihood ratio test result with p -value > 0.05 and
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48 156 Variance inflation factor less than 10 indicating the non-existence of multi-collinearity among
49
50 157 the independent variables.

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3 158 The multivariable binary logistic regression model was used to identify the independent factors
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5 159 associated with longer-term unmet supportive care needs. The summary measures of estimated
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8 160 crude (COR) and adjusted odds ratios (AOR) with 95% confidence interval were presented and
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10 161 P-value less than 0.05 was used to declare statistical significance and goodness of fit of the
11
12 162 model was assessed by using Hosmer and Lemeshow goodness of fit test. Finally, the results
13
14
15 163 were presented in statements, tables, and figures.

164 **Patient and public involvement**

165 A standard tool was used to collect outcome measures of Longer-Term Unmet Supportive Care
166 Needs (LUNs) questions, was used to collect the data. The interviewer-administered
167 questionnaire was prepared in English then translated into the local language (Amharic) and re-
168 translated back to English to maintain its consistency. The Amharic version was pretested on
169 10% of the study participants to check the clarity of the questions and receive feedback from the
170 respondents. Consent was received from each participant before the data collection and the data
171 collectors were trained to provide any information or clarification at any time of the interview.
172 Only participants who wish to continue the study after informed consent were included in the
173 study. The study results are disseminated to the neurology OPD of both hospitals to raise
174 awareness on the unmet needs of the patients so that the health professionals will start to give
175 more emphasis on the most reported unmet needs.

176 **Results**

177 **Sociodemographic characteristics**

178 A total of 422 adult stroke survivors were included in this study, making the response rate 100%.
179 Concerning the sex distribution, 243 (57.6%) of the survivors were males. The overall median
180 age of the survivors was 54.5 years with IQR (43-62) years. Three hundred thirty-eight (80.1%)

181 of the survivors were urban residents and 307 (72.7%) were from Addis Ababa. One hundred
 182 seven (25.4%) of the survivors have a diploma or degree (Table 1).

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

Variables	Categories	Frequency	Percent (%)
Age, median (25 th -75 th), 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 ^a	96	22.9
	Unemployed	39	9.3

	Housewife	15	3.6
	Others ^w	19	4.5
Monthly income (In USD) (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)	≤ 5 members	276	67.3
	> 5 members	134	32.7

185 **Abbreviations:** ^aNGO: Non-governmental organization. USD: United States Dollar. #**others:** Afar,
186 Southern Nations, nationalities and peoples regional state. Others^w: Student, and daily laborer.

187 **Clinical characteristics of participants**

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

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

Patient profile	Categories	Frequency	Percentage (%)
Stroke type	Ischemic	360	85.3
	Hemorrhagic	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

197 **Abbreviation:** [‡]mRS: Modified Rankin Scale

198 **Physiotherapy service utilization**

199 One hundred fifty-seven (37.2%) stroke survivors utilized physiotherapy services, and 265
200 (62.8%) of the survivors do not utilize physiotherapy services. Among those who utilized
201 physiotherapy service, 13(8.3%) were receiving physiotherapy every day excluding weekends
202 and holidays, meanwhile, 56 (35.7%) of the survivors utilized 2-3 times per week for 30-45
203 minutes. On the other hand, 61 (38.8%) of the survivors utilized physiotherapy less than two
204 times a week, and 27 (17.2%) of the survivors utilized physiotherapy irregularly. Financial
205 problems, lack of transport service, and unsatisfied with the physiotherapy service were the
206 reasons for not utilizing physiotherapy service reported by 100 (38.2%), 54 (20.6%), and 108
207 (41.2%) survivors respectively.

208 **The magnitude of unmet supportive care needs**

209 All stroke survivors reported at least one unmet need, 416 (98.6%) survivors stated that they
210 need more information about their stroke, why it happened, and how to avoid having another
211 one. The next two common unmet needs were, seeking advice on how to use public
212 transportation reported by, 340 (80.6%) and seeking advice on modifying their diet reported by
213 335 (79.4%) (Table 3). Two hundred twenty-six (53.6%) stroke survivors had longer-term
214 unmet supportive care needs (LUNs), and 196 (46.4%) survivors had no longer-term unmet
215 supportive care needs.

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

Longer-Term Unmet Supportive Care Needs (LUNs) questions	Patient Response	
	Yes	No
	Frequency (%)	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 traveling 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)

222 Factors associated with Longer-Term Unmet needs

223 In the final multivariable binary logistic regression model, after controlling the effect of other
 224 confounders, hypertensive stroke survivors are four times more likely to have Longer-Term
 225 Unmet Supportive Care Needs than non-hypertensive survivors with (AOR= 4.59; 95% CI 2.61-

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3 226 8.07). Similarly, those stroke survivors who have heart disease are two times more likely to have
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5 227 long-term unmet supportive care needs than those who do not have heart disease (AOR=1.94;
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8 228 95% CI 1.19-3.82).

9
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11 229 Those stroke survivors who have a moderate and above level of disability according to the
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13 230 Modified Rankin Scale (mRS) score have a very significant longer-term unmet supportive care
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15 231 needs than those who have no symptoms at all with (AOR=26.4; 95% CI 8.61-80.92). Stroke
16
17 232 survivors who utilized physiotherapy services are three times less likely to have longer-term
18
19 233 unmet supportive care needs than those who do not use physiotherapy services (AOR= 2.85; 95%
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22 234 CI 1.63-4.99) (Table 4).

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242 Table 4: Factors associated with longer-term unmet supportive care needs among adult stroke survivors, Addis Ababa, Ethiopia, 2020
 243 (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)				Ref (1)
	45-54	59 (14)	40 (9.5)	0.87	0.62	0.59 (0.27,1.26)	0.17
	55-64	61 (14.5)	57 (13.5)	1.20	0.49	0.99 (0.47,2.07)	0.98
	65-74	32 (7.6)	23 (5.5)	0.92	0.81	0.38 (0.15,1.97)	0.17
	≥ 75	11 (2.6)	27 (6.3)	3.16	0.00	1.72 (0.62,4.76)	0.29
Gender	Male	129 (30.6)	114 (27)				Ref (1)
	Female	97 (23)	82 (19.4)	0.96	0.82		
Residence	Urban	193 (45.7)	145 (34.4)				Ref (1)
	Rural	33 (7.8)	51 (12.1)	2.06	0.00	2.54 (0.93,6.89)	0.07
Region	Addis Ababa	171 (40.5)	136 (32.2)				Ref (1)
	Out of Addis Ababa	55 (13)	60 (14.3)	1.37	0.15	0.96 (0.38,2.40)	0.93
Marital status	Married	149 (35.3)	133 (31.5)				Ref (1)
	Never married	20 (4.7)	30 (7.1)	1.68	0.1	1.56 (0.68,3.59)	0.29
	Divorced	12 (2.8)	20 (4.7)	1.87	0.1	0.73 (0.26,2.05)	0.09
	Common law	45 (10.7)	13 (3.1)	0.32	0.00	0.50 (0.23,1.11)	0.55
Educational level	Able to read, write and above	204 (48.3)	178 (42.2)				Ref (1)
	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)				Ref (1)
	Non-government employee	159 (38)	122 (29.1)	0.68	0.07	0.69 (0.31,1.04)	0.2
Monthly income (In USD) (n=419)	> 120	71 (17)	57 (13.6)				Ref (1)
	≤ 120	153 (36.5)	138 (32.9)	1.12	0.59		
Family size (n=410)	≤ 5 members	141 (34.4)	135 (32.9)				Ref (1)
	> 5 members	73 (17.8)	61 (14.9)	0.87	0.52		
Stroke type	Ischemic	196 (46.5)	164 (38.9)				Ref (1)

	Hemorrhagic	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)				Ref (1)
	< 12 months	72 (17.1)	85 (20.2)	1.64	0.02	0.57 (0.31,1.04)	0.07
History of recurrence	No	127 (30.1)	103 (24.4)				Ref (1)
	Yes	99 (23.5)	93 (22)	1.16	0.45		
History of hypertension	No	122 (28.9)	41 (9.7)				Ref (1)
	Yes	104 (24.6)	155 (36.7)	4.43	<0.0001	4.59 (2.61,8.07)	<0.0001**
History of DM	No	174 (41.2)	134 (31.8)				Ref (1)
	Yes	52 (12.3)	62 (14.7)	1.55	0.05	0.63 (0.35,1.14)	0.13
History of heart diseases	No	201 (47.6)	139 (32.9)				Ref (1)
	Yes	25 (5.9)	57 (13.5)	3.30	<0.0001	1.94 (1.19,3.82)	0.04**
Level of disability according to mRS [‡]	No symptoms at all	47 (11.1)	12 (2.8)				Ref (1)
	No significant disability	111 (26.3)	48 (11.4)	1.69	0.15	1.66 (0.73,3.81)	0.23
	Slight disability	52 (12.3)	70 (16.6)	5.27	<0.0001	4.59 (1.94,10.83)	0.001**
	Moderate disability and above	16 (3.8)	66 (15.6)	16.16	<0.0001	26.4 (8.61,80.92)	<0.0001**
Physiotherapy Utilization	Yes	100 (23.7)	57 (13.5)				Ref (1)
	No	126 (29.9)	139 (32.9)	1.94	0.001	2.85 (1.63,4.99)	<0.0001**

244 Abbreviations: AOR= Adjusted odds ratio, COR= Crude odds ratio, CI= confidence interval, DM: Diabetes Mellitus, [‡]mRS: Modified Rankin
 245 Scale, ** indicates the variables were significant at P<0.05, Ref= reference group (those least to have longer-term unmet supportive care needs
 246 were considered as a reference group).

247

248 **Discussion**

249 **Background**

250 This study assessed the magnitude of the longer-term unmet supportive care needs and its
251 associated factors among adult stroke survivors in Tikur Anbessa Specialized Hospital and Saint
252 Paul's Hospital Millennium Medical College. We found that being hypertensive, having heart
253 disease, moderate and above level of disability according to the Modified Rankin Scale score,
254 unable to use the physiotherapy service were the factors associated with the higher experience of
255 the Longer-Term Unmet Supportive Care Needs.

256 **Socio-demographic Characteristics**

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

265 **Clinical Characteristics**

266 History of hypertension was reported by 61 % of stroke survivors. Similarly, another study
267 conducted in Addis Ababa Ethiopia mentioned that hypertension occurred in 65% of the total
268 study participants irrespective of their stroke type. In this study, the history of heart disease was
269 significantly associated with longer-term unmet supportive care needs, this finding goes in line

270 with a study conducted in Europe by which patients who had comorbidities reported more unmet
271 needs than the others.¹⁹

272 The level of disability according to the Modified Rankin Scale was significantly associated with
273 longer-term unmet needs. This finding was consistent with a study conducted in Germany by
274 which the level of disability of stroke survivors was significantly associated with unmet
275 psychosocial supportive care needs.²⁰

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

281 **The magnitude of unmet needs**

282 The magnitude of unmet supportive care needs in this study ranges from 26.1% (Driving needs)
283 to 98.6% (Information needs). Similarly, a study conducted in Germany found that 54% of
284 survivors reported they need more information about the cause of their stroke and prevention of
285 recurrence.²⁰ In our study 54% reported needs related to pain management (they have constant
286 pain and nothing seems to ease it). On the other hand, a study conducted in England stated that
287 only 39.5% of stroke survivors reported unmet needs regarding pain.¹⁰ This difference might be
288 as a result of the medical and rehabilitation system differences of the two countries.

289 Needing advice on getting back to driving was one of the least reported unmet needs (26.1%)
290 while seeking information on how to use public transportation again was one of the highly
291 reported unmet needs (80.6%). Similar findings were reported in Europe regarding transport and
292 travel concerns.²¹ Adaptations or aids like a stairlift, grab rails inside the home are reported by

293 53.1% of the study respondents in this study, whereas adaptations outside the home such as a
294 ramp, rail, or wheelchair were reported by half of the respondents (50.2%).

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

300 In our study, we found that sexuality needs were reported by 49.3% of the participants. Intimacy
301 problems are mentioned as one of the most commonly reported emotional problems after stroke
302 according to the study conducted in USA²³ and a study conducted in Europe.¹⁰ This figure was
303 low and should be understood with attention because talking about sex is taboo or embarrassing
304 in the culture of our setup so patients might not be honest about sexual relationship questions.
305 Moreover, this might eventually make patients distinguish that sexuality is of little significance
306 despite having certain sexual problems.

307 **Limitations of this study**

308 The study was not without limitations, stroke survivors coming to the facility might have more
309 comorbidities and thus report more unmet needs than stroke survivors in the community. Even
310 though the sample size is adequate, generalization is limited by the sampling method used. Since
311 qualitative data was not collected, a detailed understanding of the longer-term unmet needs
312 among stroke survivors is limited. Acknowledging these potential limitations we hope that this
313 finding can serve as baseline information for further research.

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3 316 **Conclusions**

4
5 317 We have found a significant proportion of adult stroke survivors having a longer-term unmet
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7 318 supportive care need. The factors associated with longer-term unmet supportive care needs were;
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9 319 having comorbidities, moderate and above level of disability according to the modified Rankin
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11 320 Scale score, and unable to use the physiotherapy service.

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15
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22
23 325 **Competing interests:** None declared.

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25
26 326 **Contributors:** EGT: project inception, management, statistical analysis and overall write up.
27
28 327 YMY: project inception, questionnaire design. SG and ZHG conducted the statistical analysis
29
30 328 and interpreted the findings, MG: project inception, questionnaire design and supervision. All
31
32 329 contributed to this manuscript and approved the final draft.

33
34 330 **Patient consent for publication:** Not required.

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37 331 **Ethics approval:** The study received approval from the institutional review board of the School
38
39 332 of Public Health, Addis Ababa University (Ref: SPH/005/2020). Furthermore, the study received
40
41 333 an ethical approval from both hospitals where the study was conducted before data collection
42
43 334 was started. Consent was received from study participants after a clear explanation of the
44
45 335 objectives, benefits and risks of
46
47 336 the study. The participants were also given the right to discontinue anytime if they don't feel like
48
49 337 participating.

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339 **Data availability statement:** The datasets generated and analyzed during the current study are
340 available from the corresponding author on a reasonable request.

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406 **Figure legends**

407 Figure 1: Score of Modified Rankin Scale among adult stroke survivors with and without Long
408 Term Unmet Supportive Care Needs receiving routine follow-up services Addis Ababa,
409 Ethiopia, 2020 (n=422).
410

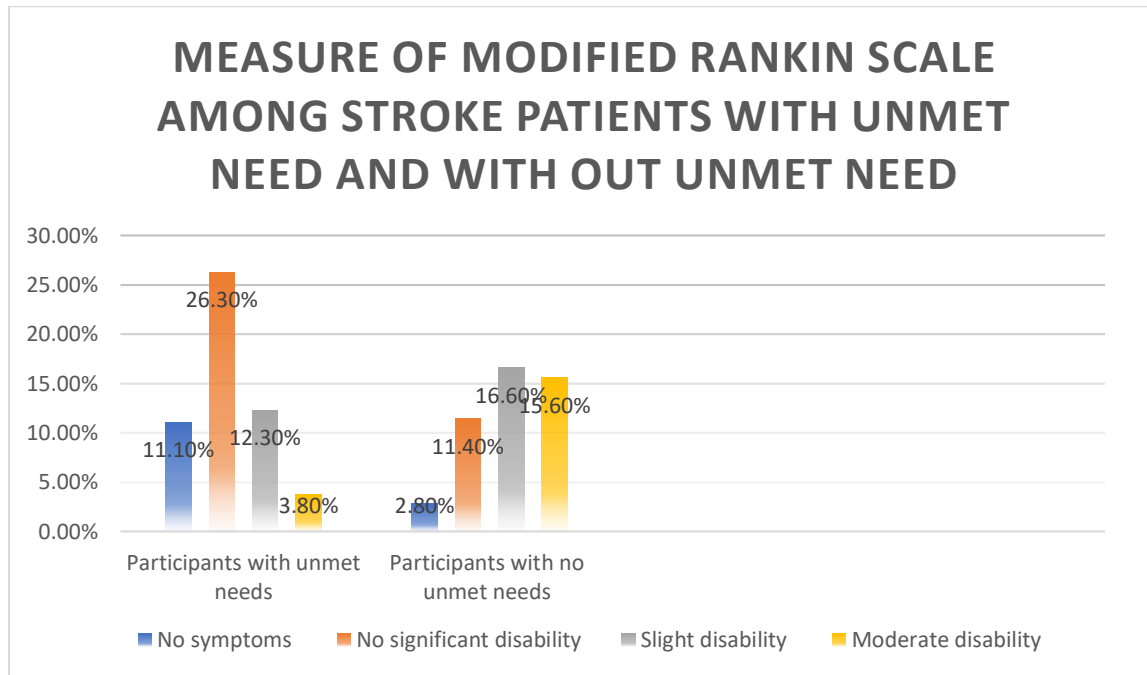


Figure 1: Score of Modified Rankin Scale among adult stroke survivors with and without Long Term Unmet Supportive Care Needs receiving routine follow-up services Addis Ababa, Ethiopia, 2020 (n=422).

STROBE 2007 (v4) checklist of items to be included in reports of observational studies in epidemiology*
Checklist for cohort, case-control, and cross-sectional studies (combined)

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	1 and 2
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	3
Objectives	3	State specific objectives, including any pre-specified hypotheses	4
Methods			
Study design	4	Present key elements of study design early in the paper	5
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5
Participants	6	(a) <i>Cohort study</i> —Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up <i>Case-control study</i> —Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls <i>Cross-sectional study</i> —Give the eligibility criteria, and the sources and methods of selection of participants	5
		(b) <i>Cohort study</i> —For matched studies, give matching criteria and number of exposed and unexposed <i>Case-control study</i> —For matched studies, give matching criteria and the number of controls per case	6
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	6
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	-
Bias	9	Describe any efforts to address potential sources of bias	
Study size	10	Explain how the study size was arrived at	6
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	7
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	6
		(b) Describe any methods used to examine subgroups and interactions	
		(c) Explain how missing data were addressed	
		(d) <i>Cohort study</i> —If applicable, explain how loss to follow-up was addressed <i>Case-control study</i> —If applicable, explain how matching of cases and controls was addressed	6

		<i>Cross-sectional study</i> —If applicable, describe analytical methods taking account of sampling strategy	
		(e) Describe any sensitivity analyses	
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	8
		(b) Give reasons for non-participation at each stage	8
		(c) Consider use of a flow diagram	-
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	9, 10, 11
		(b) Indicate number of participants with missing data for each variable of interest	
		(c) <i>Cohort study</i> —Summarise follow-up time (eg, average and total amount)	
Outcome data	15*	<i>Cohort study</i> —Report numbers of outcome events or summary measures over time	
		<i>Case-control study</i> —Report numbers in each exposure category, or summary measures of exposure	
		<i>Cross-sectional study</i> —Report numbers of outcome events or summary measures	13
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	-
		(b) Report category boundaries when continuous variables were categorized	-
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	-
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	-
Discussion			
Key results	18	Summarise key results with reference to study objectives	17
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	19
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	20
Generalisability	21	Discuss the generalisability (external validity) of the study results	19
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	-

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at www.strobe-statement.org.

BMJ Open

Factors associated with the Longer-Term Unmet Supportive Care Needs of Stroke Survivors in Ethiopia: A multi-center cross-sectional study

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4 1 **Original research**
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9 3 **Factors associated with the Longer Term Unmet Supportive Care Needs of**
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12 4 **Stroke Survivors in Ethiopia: A multi-center cross sectional study**
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18 7 Edna Gebremichael Tamrat^{1*}, Zenawi Hagos Gufue³, Sefonias Getachew¹, Yared Mamushet
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23 Abstract

24 **Objectives:** To assess the magnitude of the Longer-Term Unmet Supportive Care Needs and
25 associated factors among adult Stroke Survivors.

26 **Design:** An institutional-based multi-center cross-sectional study.

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

28 **Participants:** Adult Stroke Survivors (aged ≥ 18 years, n=422), diagnosed with a stroke at least
29 six months before the study period and who started regular follow-up at the Neurology
30 Outpatient clinics in Addis Ababa, Ethiopia.

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

32 **Results:** Two hundred twenty-six (53.6%) stroke survivors had longer-term unmet supportive
33 care needs, and 196 (46.4%) survivors had no longer-term unmet supportive care needs.
34 Information need about stroke reported by 416 (98.6%), and how to travel on public
35 transportation reported by 340 (80.6%) survivors were the most frequently reported unmet needs.
36 Stroke survivors longer term unmet supportive care needs were significantly associated with
37 being hypertensive with (AOR= 4.59; 95% CI 2.61-8.07), having heart disease with (AOR=1.94;
38 95% CI 1.19-3.82), moderate and above level of disability according to the modified Rankin
39 Scale score with (AOR=26.4; 95% CI 8.61-80.92), and unable to use the physiotherapy service
40 with (AOR= 2.85; 95% CI of 1.63-4.99).

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

46 **Strengths and limitations of this study**

47 ✚ This was the first local study using the standardized instrument for measuring stroke patients'
48 longer-term unmet needs and this can serve as baseline information for further research in
49 Ethiopia and Sub-Saharan Africa.

50 ✚ The previous studies were mainly focused on the descriptive summary of the unmet needs,
51 but this study tried to identify the factors associated with stroke survivor's longer-term unmet
52 needs.

53 ✚ Stroke survivors coming to the facility might have more comorbidities and thus report more
54 unmet needs than stroke survivors in the community. Even though the sample size is
55 adequate, generalization is limited by the sampling method used.

56 ✚ Since qualitative data was not collected, a detailed understanding of the longer-term unmet
57 needs among stroke survivors is limited.

58 **Introduction**

59 Globally, stroke is the second leading cause of death following ischemic heart disease, being
60 responsible for 8.76 million deaths, and taking lives every five seconds. Stroke is the second
61 most common cause of adult disability (4.6%) of the global Disability Adjusted Life Years
62 (DALYs).¹ Without significant interventions, the global stroke mortality is estimated to rise to
63 7.8 million deaths per year by the end of 2030.² The global economic cost of adult stroke is more
64 than 25 billion dollars per year.³ (Figure 1)

65 Supportive care is defined as, rendering essential services that satisfy stroke patients' physical,
66 psychological, social, informational, and spiritual needs over the entire illness trajectory.

67 Supportive care is an essential buffering component of stroke survivors that helps to regain

1
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3 68 emotional stability, social adjustment, cognitive function, body image, future perspective, and
4
5 69 physical recovery.⁴
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8 70 In Sub-Saharan Africa (SSA), stroke primarily affects the young and productive segment of the
9
10 71 population.^{5,6} The development of appropriate service provision is limited by the lack of
11
12 72 vigorous estimates of longer-term outcomes after stroke and the prevalence of stroke survivors in
13
14 73 SSA was reported to be 14.6/1,000 people.⁷ High burden of uncontrolled vascular risk factors
15
16 74 due to low screening and treatment modalities, uncoordinated, and fragmentary acute stroke care,
17
18 75 and limited rehabilitation services were described as factors associated with poor prognosis after
19
20 76 Stroke.^{5,7} The increase in the magnitude of Stroke, thus calls the urge to identify their unmet
21
22 77 needs to accelerate their recovery.⁸
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26

27 78 In Sub-Saharan Africa, the physiotherapists to population ratio range from 0.1/100,000 people in
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29 79 Ethiopia to 6.7/100,000 people in South Africa.⁵ There is a high mismatch in the longer-term
30
31 80 stroke rehabilitation care need and delivery. Longer-term supportive care service delivery should
32
33 81 be patient-oriented and designed compatible with the local situation.⁹ Therefore, assessing the
34
35 82 needs of stroke survivors is essential to improve stroke survivors' quality of life.^{9, 10} Even though
36
37 83 the unmet need for supportive care for cancer and chronic kidney failure patients is documented,
38
39 84 much attention was not given to the supportive care services among stroke survivors.⁴
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44 85 To the best of our knowledge, we did not get studies conducted in Sub-Saharan Africa, including
45
46 86 in Ethiopia, which determines the longer-term unmet supportive care needs, and associated
47
48 87 factors among adult stroke survivors. This study intended to assess the magnitude of the longer-
49
50 88 term unmet supportive care needs, and associated factors among adult stroke survivors in Tikur
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52 89 Anbessa Specialized Hospital and Saint Paul's Hospital Millennium Medical College, Addis
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54 90 Ababa, Ethiopia.
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91 **Methods and Materials**

92 The study was conducted in Tikur Anbessa Specialized Hospital (TASH) and Saint Paul's
93 Hospital Millennium Medical College (SPHMMC) in Addis Ababa, the capital city of Ethiopia.
94 TASH is the first largest government-owned hospital serving as a teaching hospital of Addis
95 Ababa University and a major referral center from all over the country. TASH provides service
96 to different Neurologic cases at the Neurology Outpatient Department (OPD) twice a week and
97 allocated one additional day to treat stroke survivors in the OPD. SPHMMC is the second-largest
98 hospital in Ethiopia following TASH. It treats neurologic cases four days a week in the
99 Neurology OPD. The study was conducted from March 1, 2020, to May 31, 2020.

100 **Study design:** An institutional-based multi-center cross-sectional study was conducted.

101 **Participants:** Those adult stroke survivors (aged ≥ 18 years) who were diagnosed with stroke at
102 least 6-months before the study period and who started follow up at the Neurology Outpatient
103 Departments of TASH and SPHMMC were considered as the study population. Those stroke
104 survivors who were not able to represent themselves, who didn't have anyone to represent them
105 as a caregiver were excluded from the study.

106 **Sample size determination and sampling technique**

107 The sample size was determined by applying a single population proportion formula using Epi
108 Info version 7.2.4.0 software¹¹, with the assumptions of a 95% level of confidence, a 5% margin
109 of error. Since we couldn't find any previous studies conducted in Africa to determine the
110 longer-term unmet supportive care needs among adult stroke survivors, the sample size was
111 calculated by taking the largest sample size to detect a statistically significant difference.
112 Accordingly, the percent of stroke survivors who have long-term unmet supportive care needs

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3 113 50%, with these assumptions the sample size was 384, and after adding a 10% non-response rate
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5 114 the final sample size was 422.

6 7 8 115 **Sampling procedure**

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10 116 A convenience sampling technique was used to select the study participants, accordingly, all
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12 117 adult stroke survivors who were available at the Neurology OPDs of TASH and SPHMMC
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15 118 during the study period who meet the inclusion criteria were included in the study.

16 17 119 **Data collection instrument**

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19 120 A pre-tested structured interviewer-administered questionnaire, which contains the socio-
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21 121 demographic, clinical, neurological factors, and the Longer Term Unmet Supportive Care Needs
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23 122 (LUNs) questions, was used to collect the data. The interviewer-administered questionnaire was
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26 123 prepared in English then translated into the local language (Amharic) and re-translated back to
27
28 124 English to maintain its consistency. The level of disability of the stroke survivors was measured
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30
31 125 by using the Modified Rankin Scale (mRS).¹²

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34 126 The LUNs is a 22-item standardized instrument for measuring stroke patients' longer-term unmet
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36 127 needs.¹³ The 22 variables that were included in the LUNs tool were combined into one by
37
38 128 calculating the mean, the mean of these variables was further dichotomized by calculating its
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41 129 population mean as having no unmet need and having an unmet need. If a patient-reported an
42
43 130 unmet need that was above the population mean, it is considered as having an unmet need. On
44
45 131 the other hand, if a patient reports unmet needs below the mean value it was considered as
46
47
48 132 having no unmet need.

49 50 133 **Operational definitions**

51
52 134 Stroke survivor: is a person who has had a stroke attack previously and is not currently receiving
53
54 135 acute comma care or receiving an inpatient treatment in a hospital setting.¹⁴ Longer Term

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3 136 Supportive Care Needs: These includes physical relationships, managing money, accessible
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5 137 holidays, pain, driving, memory, information, employment, benefits, daily occupations, bladder
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8 138 control, mood, adaptations outside, diet, home help, moving house, transportation, adaptations
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10 139 inside, falling, mobility, blood pressure.¹⁵

11
12 140 Needs: Issues and/or actions that are deemed necessary by the survivor to manage his/her
13
14 141 wellbeing and best quality of care. An unmet need: a problem that was not being addressed or
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16
17 142 one that was being addressed, but insufficiently. Longer-term unmet need: unmet needs that exist
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19 143 at least after 6-month post-stroke.¹⁵ Having Longer-term unmet need: having unmet needs that
20
21 144 exist at least after 6-month post-stroke which are above the calculated mean value.

22 23 24 145 **Data processing, management, and analysis**

25
26 146 The collected data was coded and checked for its consistency and completeness up to the end of
27
28 147 each data collection period. Before the analysis, the whole data were cleaned and 20% of the data
29
30
31 148 were double-entered randomly to check for data entry errors, and Epi Info version 7.2.4.0
32
33 149 software¹¹ was used for data entry. The entered data were exported to STATA version 14.0 for
34
35 150 windows.¹⁶ Descriptive statistics were presented in medians with interquartile range for
36
37 151 numerical variables and categorical variables were presented using frequency and percentages.

38
39
40 152 The bivariate analysis was done to check the existence of crude association and to select
41
42 153 candidate variables, those variables which are clinically important and having ($P < 0.25$) were
43
44
45 154 included in the final model.¹⁷ Confounding was checked, and percentage change in the regression
46
47 155 coefficients (β) less than 20% reveals an absence of confounder. Interaction for the main effect
48
49 156 model was also be checked and partial likelihood ratio test result with p-value > 0.05 and
50
51 157 Variance inflation factor less than 10 indicating the non-existence of multi-collinearity among
52
53 158 the independent variables.

159 The multivariable binary logistic regression model was used to identify the independent factors
160 associated with longer-term unmet supportive care needs. The summary measures of estimated
161 crude (COR) and adjusted odds ratios (AOR) with 95% confidence interval were presented and
162 P-value less than 0.05 was used to declare statistical significance and goodness of fit of the
163 model was assessed by using Hosmer and Lemeshow goodness of fit test. Finally, the results
164 were presented in statements, tables, and figure.

165 **Patient and public involvement**

166 A standard tool was used to collect outcome measures of Longer-Term Unmet Supportive Care
167 Needs (LUNs) questions, was used to collect the data. The interviewer-administered
168 questionnaire was prepared in English then translated into the local language (Amharic) and re-
169 translated back to English to maintain its consistency. The Amharic version was pretested on
170 10% of the study participants to check the clarity of the questions and receive feedback from the
171 respondents. Consent was received from each participant before the data collection and the data
172 collectors were trained to provide any information or clarification at any time of the interview.
173 Only participants who wish to continue the study after informed consent were included in the
174 study. The study results are disseminated to the neurology OPD of both hospitals to raise
175 awareness on the unmet needs of the patients so that the health professionals will start to give
176 more emphasis on the most reported unmet needs.

177 **Results**

178 **Sociodemographic characteristics**

179 A total of 422 adult stroke survivors were included in this study, making the response rate 100%.
180 Concerning the sex distribution, 243 (57.6%) of the survivors were males. The overall median
181 age of the survivors was 54.5 years with IQR (43-62) years. Three hundred thirty-eight (80.1%)

182 of the survivors were urban residents and 307 (72.7%) were from Addis Ababa. One hundred
 183 seven (25.4%) of the survivors have a diploma or degree (Table 1).

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

Variables	Categories	Frequency	Percent (%)
Age, median (25 th -75 th), 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 ^a	96	22.9
	Unemployed	39	9.3

	Housewife	15	3.6
	Others ^w	19	4.5
Monthly income (In USD) (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)	≤ 5 members	276	67.3
	> 5 members	134	32.7

186 **Abbreviations:** ^aNGO: Non-governmental organization. USD: United States Dollar. #**others:** Afar,
187 Southern Nations, nationalities and peoples regional state. Others^w: Student, and daily laborer.

188 **Clinical characteristics of participants**

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

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

Patient profile	Categories	Frequency	Percentage (%)
Stroke type	Ischemic	360	85.3
	Hemorrhagic	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

198 **Abbreviation:** [‡]mRS: Modified Rankin Scale

199 **Physiotherapy service utilization**

200 One hundred fifty-seven (37.2%) stroke survivors utilized physiotherapy services, and 265
201 (62.8%) of the survivors do not utilize physiotherapy services. Among those who utilized
202 physiotherapy service, 13(8.3%) were receiving physiotherapy every day excluding weekends
203 and holidays, meanwhile, 56 (35.7%) of the survivors utilized 2-3 times per week for 30-45
204 minutes. On the other hand, 61 (38.8%) of the survivors utilized physiotherapy less than two
205 times a week, and 27 (17.2%) of the survivors utilized physiotherapy irregularly. Financial
206 problems, lack of transport service, and unsatisfied with the physiotherapy service were the
207 reasons for not utilizing physiotherapy service reported by 100 (38.2%), 54 (20.6%), and 108
208 (41.2%) survivors respectively.

209 **The magnitude of unmet supportive care needs**

210 All stroke survivors reported at least one unmet need, 416 (98.6%) survivors stated that they
211 need more information about their stroke, why it happened, and how to avoid having another
212 one. The next two common unmet needs were, seeking advice on how to use public
213 transportation reported by, 340 (80.6%) and seeking advice on modifying their diet reported by
214 335 (79.4%) (Table 3). Two hundred twenty-six (53.6%) stroke survivors had longer-term
215 unmet supportive care needs (LUNs), and 196 (46.4%) survivors had no longer-term unmet
216 supportive care needs.

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

Longer-Term Unmet Supportive Care Needs (LUNs) questions	Patient Response	
	Yes	No
	Frequency (%)	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 traveling 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)

223 Factors associated with Longer-Term Unmet needs

224 In the final multivariable binary logistic regression model, after controlling the effect of other
 225 confounders, hypertensive stroke survivors are four times more likely to have Longer-Term
 226 Unmet Supportive Care Needs than non-hypertensive survivors with (AOR= 4.59; 95% CI 2.61-

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3 227 8.07). Similarly, those stroke survivors who have heart disease are two times more likely to have
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5 228 long-term unmet supportive care needs than those who do not have heart disease (AOR=1.94;
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8 229 95% CI 1.19-3.82).

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11 230 Those stroke survivors who have a moderate and above level of disability according to the
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13 231 Modified Rankin Scale (mRS) score have a very significant longer-term unmet supportive care
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15 232 needs than those who have no symptoms at all with (AOR=26.4; 95% CI 8.61-80.92). Stroke
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17 233 survivors who utilized physiotherapy services are three times less likely to have longer-term
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19 234 unmet supportive care needs than those who do not use physiotherapy services (AOR= 2.85; 95%
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22 235 CI 1.63-4.99) (Table 4).

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243 Table 4: Factors associated with longer-term unmet supportive care needs among adult stroke survivors, Addis Ababa, Ethiopia, 2020
 244 (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)				Ref (1)
	45-54	59 (14)	40 (9.5)	0.87	0.62	0.59 (0.27,1.26)	0.17
	55-64	61 (14.5)	57 (13.5)	1.20	0.49	0.99 (0.47,2.07)	0.98
	65-74	32 (7.6)	23 (5.5)	0.92	0.81	0.38 (0.15,1.97)	0.17
	≥ 75	11 (2.6)	27 (6.3)	3.16	0.00	1.72 (0.62,4.76)	0.29
Gender	Male	129 (30.6)	114 (27)				Ref (1)
	Female	97 (23)	82 (19.4)	0.96	0.82		
Residence	Urban	193 (45.7)	145 (34.4)				Ref (1)
	Rural	33 (7.8)	51 (12.1)	2.06	0.00	2.54 (0.93,6.89)	0.07
Region	Addis Ababa	171 (40.5)	136 (32.2)				Ref (1)
	Out of Addis Ababa	55 (13)	60 (14.3)	1.37	0.15	0.96 (0.38,2.40)	0.93
Marital status	Married	149 (35.3)	133 (31.5)				Ref (1)
	Never married	20 (4.7)	30 (7.1)	1.68	0.1	1.56 (0.68,3.59)	0.29
	Divorced	12 (2.8)	20 (4.7)	1.87	0.1	0.73 (0.26,2.05)	0.09
	Common law	45 (10.7)	13 (3.1)	0.32	0.00	0.50 (0.23,1.11)	0.55
Educational level	Able to read, write and above	204 (48.3)	178 (42.2)				Ref (1)
	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)				Ref (1)
	Non-government employee	159 (38)	122 (29.1)	0.68	0.07	0.69 (0.31,1.04)	0.2
Monthly income (In USD) (n=419)	> 120	71 (17)	57 (13.6)				Ref (1)
	≤ 120	153 (36.5)	138 (32.9)	1.12	0.59		
Family size (n=410)	≤ 5 members	141 (34.4)	135 (32.9)				Ref (1)
	> 5 members	73 (17.8)	61 (14.9)	0.87	0.52		
Stroke type	Ischemic	196 (46.5)	164 (38.9)				Ref (1)

	Hemorrhagic	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)				Ref (1)
	< 12 months	72 (17.1)	85 (20.2)	1.64	0.02	0.57 (0.31,1.04)	0.07
History of recurrence	No	127 (30.1)	103 (24.4)				Ref (1)
	Yes	99 (23.5)	93 (22)	1.16	0.45		
History of hypertension	No	122 (28.9)	41 (9.7)				Ref (1)
	Yes	104 (24.6)	155 (36.7)	4.43	<0.0001	4.59 (2.61,8.07)	<0.0001**
History of DM	No	174 (41.2)	134 (31.8)				Ref (1)
	Yes	52 (12.3)	62 (14.7)	1.55	0.05	0.63 (0.35,1.14)	0.13
History of heart diseases	No	201 (47.6)	139 (32.9)				Ref (1)
	Yes	25 (5.9)	57 (13.5)	3.30	<0.0001	1.94 (1.19,3.82)	0.04**
Level of disability according to mRS [‡]	No symptoms at all	47 (11.1)	12 (2.8)				Ref (1)
	No significant disability	111 (26.3)	48 (11.4)	1.69	0.15	1.66 (0.73,3.81)	0.23
	Slight disability	52 (12.3)	70 (16.6)	5.27	<0.0001	4.59 (1.94,10.83)	0.001**
	Moderate disability and above	16 (3.8)	66 (15.6)	16.16	<0.0001	26.4 (8.61,80.92)	<0.0001**
Physiotherapy Utilization	Yes	100 (23.7)	57 (13.5)				Ref (1)
	No	126 (29.9)	139 (32.9)	1.94	0.001	2.85 (1.63,4.99)	<0.0001**

245 Abbreviations: AOR= Adjusted odds ratio, COR= Crude odds ratio, CI= confidence interval, DM: Diabetes Mellitus, mRS: Modified Rankin
 246 Scale, ** indicates the variables were significant at P<0.05, Ref= reference group (those least to have longer-term unmet supportive care needs
 247 were considered as a reference group).

248

249 **Discussion**

250 **Background**

251 This study assessed the magnitude of the longer-term unmet supportive care needs and its
252 associated factors among adult stroke survivors in Tikur Anbessa Specialized Hospital and Saint
253 Paul's Hospital Millennium Medical College. We found that being hypertensive, having heart
254 disease, moderate and above level of disability according to the Modified Rankin Scale score,
255 unable to use the physiotherapy service were the factors associated with the higher experience of
256 the Longer-Term Unmet Supportive Care Needs.

257 **Socio-demographic Characteristics**

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

266 **Clinical Characteristics**

267 History of hypertension was reported by 61 % of stroke survivors. Similarly, another study
268 conducted in Addis Ababa Ethiopia mentioned that hypertension occurred in 65% of the total
269 study participants irrespective of their stroke type. In this study, the history of heart disease was
270 significantly associated with longer-term unmet supportive care needs, this finding goes in line

271 with a study conducted in Europe by which patients who had comorbidities reported more unmet
272 needs than the others.¹⁹

273 The level of disability according to the Modified Rankin Scale was significantly associated with
274 longer-term unmet needs. This finding was consistent with a study conducted in Germany by
275 which the level of disability of stroke survivors was significantly associated with unmet
276 psychosocial supportive care needs.²⁰

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

282 **The magnitude of unmet needs**

283 The magnitude of unmet supportive care needs in this study ranges from 26.1% (Driving needs)
284 to 98.6% (Information needs). Similarly, a study conducted in Germany found that 54% of
285 survivors reported they need more information about the cause of their stroke and prevention of
286 recurrence.²⁰ In our study 54% reported needs related to pain management (they have constant
287 pain and nothing seems to ease it). On the other hand, a study conducted in England stated that
288 only 39.5% of stroke survivors reported unmet needs regarding pain.¹⁰ This difference might be
289 as a result of the medical and rehabilitation system differences of the two countries.

290 Needing advice on getting back to driving was one of the least reported unmet needs (26.1%)
291 while seeking information on how to use public transportation again was one of the highly
292 reported unmet needs (80.6%). Similar findings were reported in Europe regarding transport and
293 travel concerns.²¹ Adaptations or aids like a stairlift, grab rails inside the home are reported by

294 53.1% of the study respondents in this study, whereas adaptations outside the home such as a
295 ramp, rail, or wheelchair were reported by half of the respondents (50.2%).

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

301 In our study, we found that sexuality needs were reported by 49.3% of the participants. Intimacy
302 problems were mentioned as one of the most commonly reported emotional problems after
303 stroke according to the study conducted in USA²³ and in Europe¹⁰. This figure was low and
304 should be understood with attention because talking about sex is taboo or embarrassing in the
305 culture of our setup so patients might not be honest about sexual relationship questions.
306 Moreover, this might eventually make patients distinguish that sexuality is of little significance
307 despite having certain sexual problems.

308 **Limitations of this study**

309 The study was not without limitations, stroke survivors coming to the facility might have more
310 comorbidities and thus report more unmet needs than stroke survivors in the community. Even
311 though the sample size is adequate, generalization is limited by the sampling method used.
312 Dichotomizing the outcome might have disproportionally affected those who have labeled as
313 having 'no unmet needs'. Since qualitative data was not collected, a detailed understanding of
314 the longer-term unmet needs among stroke survivors is limited. In addition, even though we
315 conducted a pretest to assess the clarity of the LUNS tool a validation study was not conducted

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3 316 as the tool has never been used in Ethiopia. Acknowledging these potential limitations we hope
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5 317 that this finding can serve as baseline information for further research.
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12 320 **Conclusions**

14 321 We have found a significant proportion of adult stroke survivors having a longer-term unmet
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16 322 supportive care need. The factors associated with longer-term unmet supportive care needs were;
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18 323 having comorbidities, moderate and above level of disability according to the modified Rankin
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21 324 Scale score, and unable to use the physiotherapy service.

23
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25
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27
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29
30 328 commercial or not-for-profit sectors.

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33 329 **Competing interests:** None declared.

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35 330 **Contributors:** EGT: project inception, management, statistical analysis and overall write up.
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37 331 YMY: project inception, questionnaire design. SG and ZHG conducted the statistical analysis
38
39 332 and interpreted the findings, MG: project inception, questionnaire design and supervision. All
40
41 333 contributed to this manuscript and approved the final draft.

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44 334 **Patient consent for publication:** Not required.

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46 335 **Ethics approval:** The study received approval from the institutional review board of the School
47
48 336 of Public Health, Addis Ababa University (Ref: SPH/005/2020). Furthermore, the study received
49
50 337 an ethical approval from both hospitals where the study was conducted before data collection
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52 338 was started. Consent was received from study participants after a clear explanation of the
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339 objectives, benefits and risks of the study. The participants were also given the right to
340 discontinue anytime if they don't feel like participating.

341
342 **Data availability statement:** The datasets generated and analyzed during the current study are
343 available from the corresponding author on a reasonable request.

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31 **Figure 1**

32 410 Figure 1: Score of Modified Rankin Scale among adult stroke survivors with and without Long
33 411 Term Unmet Supportive Care Needs receiving routine follow-up services Addis Ababa,
34 412 Ethiopia, 2020 (n=422).
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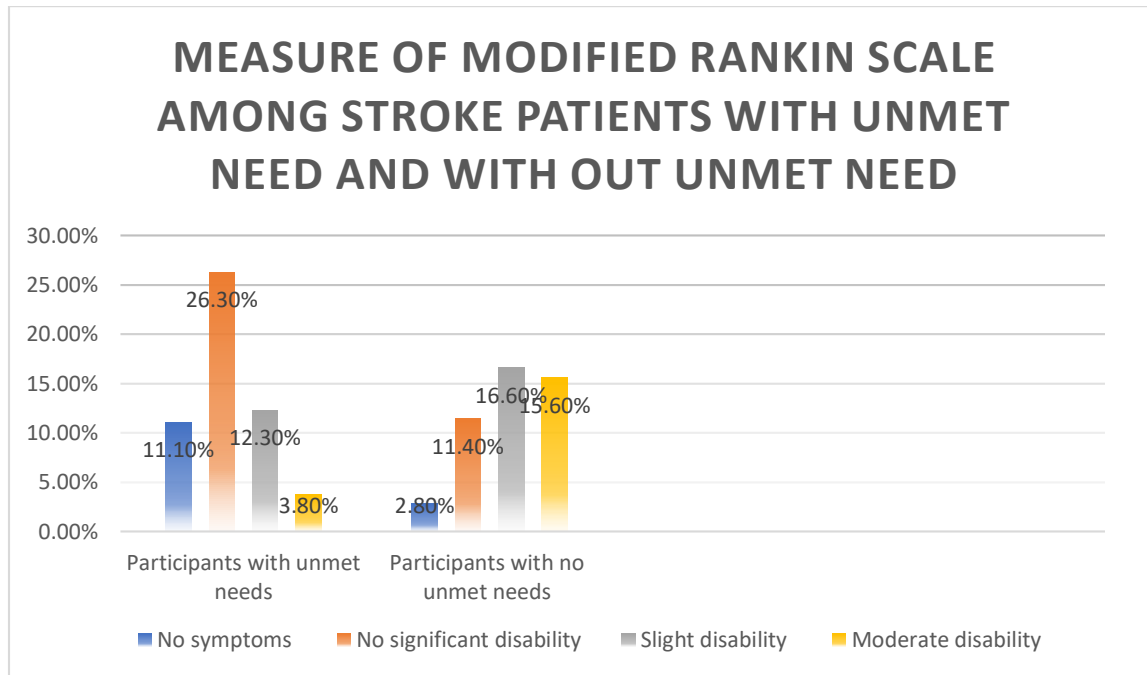


Figure 1: Score of Modified Rankin Scale among adult stroke survivors with and without Long Term Unmet Supportive Care Needs receiving routine follow-up services Addis Ababa, Ethiopia, 2020 (n=422).

STROBE 2007 (v4) checklist of items to be included in reports of observational studies in epidemiology*
Checklist for cohort, case-control, and cross-sectional studies (combined)

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	1 and 2
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	3
Objectives	3	State specific objectives, including any pre-specified hypotheses	4
Methods			
Study design	4	Present key elements of study design early in the paper	5
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5
Participants	6	(a) <i>Cohort study</i> —Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up <i>Case-control study</i> —Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls <i>Cross-sectional study</i> —Give the eligibility criteria, and the sources and methods of selection of participants	5
		(b) <i>Cohort study</i> —For matched studies, give matching criteria and number of exposed and unexposed <i>Case-control study</i> —For matched studies, give matching criteria and the number of controls per case	6
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	6
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	-
Bias	9	Describe any efforts to address potential sources of bias	
Study size	10	Explain how the study size was arrived at	6
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	7
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	6
		(b) Describe any methods used to examine subgroups and interactions	
		(c) Explain how missing data were addressed	
		(d) <i>Cohort study</i> —If applicable, explain how loss to follow-up was addressed <i>Case-control study</i> —If applicable, explain how matching of cases and controls was addressed	6

		<i>Cross-sectional study</i> —If applicable, describe analytical methods taking account of sampling strategy	
		(e) Describe any sensitivity analyses	
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	8
		(b) Give reasons for non-participation at each stage	8
		(c) Consider use of a flow diagram	-
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	9, 10, 11
		(b) Indicate number of participants with missing data for each variable of interest	
		(c) <i>Cohort study</i> —Summarise follow-up time (eg, average and total amount)	
Outcome data	15*	<i>Cohort study</i> —Report numbers of outcome events or summary measures over time	
		<i>Case-control study</i> —Report numbers in each exposure category, or summary measures of exposure	
		<i>Cross-sectional study</i> —Report numbers of outcome events or summary measures	13
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	-
		(b) Report category boundaries when continuous variables were categorized	-
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	-
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	-
Discussion			
Key results	18	Summarise key results with reference to study objectives	17
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	19
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	20
Generalisability	21	Discuss the generalisability (external validity) of the study results	19
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	-

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at www.strobe-statement.org.