BMJ Open

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

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2021-053579
Article Type:	Original research
Date Submitted by the Author:	19-May-2021
Complete List of Authors:	Tamrat, Edna; Addis Ababa University College of Health Sciences, Department of Preventive Medicine ; Gizaw , Muluken ; Addis Ababa University College of Health Sciences, Department of Preventive Medicine, School of Public Health Getachew, Sefonias; Addis Ababa University, Department of Preventive Medicine Yifru, Yared; Addis Ababa University College of Health Sciences, Department of Neurology, Faculty of Medicine Gufue , Zenawi; Adigrat University College of Health Sciences, Department of Public Health
Keywords:	STROKE MEDICINE, STATISTICS & RESEARCH METHODS, PUBLIC HEALTH, Adult palliative care < PALLIATIVE CARE, Stroke < NEUROLOGY, EPIDEMIOLOGY

I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our licence.

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which Creative Commons licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

Orginal research

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

Edna Gebremichael Tamrat[1*], Muluken Gizaw[1], Sefonias Getachew[1], Yared Mamushet Yifru[2], Zenawi Hagos Gufue[3]

[1*]Department of Preventive Medicine, School of Public Health, Addis Ababa University.

[2]Department of Neurology, Faculty of Medicine, Addis Ababa University

[3]Department of Public Health, College of Medicine and Health Sciences, Adigrat University

Corresponding Author

[1*]Edna Gebremichael Tamrat (BSc, MPH)

Department of Preventive Medicine, School of Public Health, Addis Ababa University.

Email: ednagtamrat@gmail.com, Phone Number: +251 920 19 74 36

P.O.BOX: 9086, website: http://www.aau.edu.et/

Addis Ababa, Ethiopia

Abstract

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

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

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

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

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

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

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

Strengths and limitations of this study

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

Introduction

Globally, stroke is the second leading cause of death following ischemic heart disease, being responsible for 8.76 million deaths, and taking lives every five seconds. Stroke is the second most common cause of adult disability (4.6%) of the global Disability Adjusted Life Years (DALYs).[1] Without significant interventions, the global stroke mortality is estimated to rise to 7.8 million deaths per year by the end of 2030.[2] The global economic cost of adult stroke is more than 25 billion dollars per year.[3]

Supportive care is defined as, rendering essential services that satisfy stroke patients' physical, psychological, social, informational, and spiritual needs over the entire illness trajectory. Supportive care is an essential buffering component of stroke survivors that helps to regain

emotional stability, social adjustment, cognitive function, body image, future perspective, and physical recovery.[4]

In Sub-Saharan Africa (SSA), stroke primarily affects the young and productive segment of the population.[5,6] The development of appropriate service provision is limited by the lack of vigorous estimates of long-term outcomes after stroke and the prevalence of stroke survivors in SSA was reported to be 14.6/1,000 people.[7] High burden of uncontrolled vascular risk factors due to low screening and treatment modalities, uncoordinated, and fragmentary acute stroke care, and limited rehabilitation services were described as factors associated with poor prognosis after Stroke.[5,7] The increase in the magnitude of Stroke, thus calls the urge to identify their unmet needs to accelerate their recovery.[8]

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

To the best of our knowledge, we did not get studies conducted in Sub-Saharan Africa, including in Ethiopia, which determines the long-term unmet supportive care needs, and associated factors among adult stroke survivors. This study was intended to assess the magnitude of the long-term unmet supportive care needs, and associated factors among adult stroke survivors in Tikur Anbessa Specialized Hospital and Saint Paul's Hospital Millennium Medical College, Addis Ababa, Ethiopia.

Methods and Materials

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

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

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

Sample size determination and sampling technique

The sample size was determined by applying a single population proportion formula using Epi Info version 7.2.4.0 software[11], with the assumptions of a 95% level of confidence, a 5% margin of error. Since we couldn't find any previous studies conducted in Africa to determine the long-term unmet supportive care needs among adult stroke survivors, the sample size was calculated by taking the largest sample size to detect a statistically significant difference. Accordingly, the percent of stroke survivors who have long-term unmet supportive care needs 50%, with these

assumptions the sample size was 384, and after adding a 10% non-response rate the final sample size was 422.

Sampling procedure

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

Data collection instrument

A pre-tested structured interviewer-administered questionnaire, which contains the socio-demographic, clinical, neurological factors, and the Long Term Unmet Supportive Care Needs (LUNs) questions, was used to collect the data. The interviewer-administered questionnaire was prepared in English then translated into the local language (Amharic) and re-translated back to English to maintain its consistency. The level of disability of the stroke survivors was measured by using the Modified Rankin Scale (mRS).[12]

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

Operational definitions

Stroke survivor: is a person who has had a stroke attack previously and is not currently receiving acute comma care.[14] Long Term Supportive Care Needs: These includes physical relationships,

managing money, accessible holidays, pain, driving, memory, information, employment, benefits, daily occupations, bladder control, mood, adaptations outside, diet, home help, moving house, transportation, adaptations inside, falling, mobility, blood pressure.[15]

Needs**:** Issues and/or actions that are deemed necessary by the survivor to manage his/her wellbeing and best quality of care. An unmet need: a problem that was not being addressed or one that was being addressed, but insufficiently. Long-term unmet need: unmet needs that exist at least after 6-month post-stroke.[15]

Data processing, management, and analysis

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

The bivariate analysis was done to check the existence of crude association and to select candidate variables, those variables which are clinically important and having ($P < 0.25$) were included in the final model.[17] Confounding was checked, and percentage change in the regression coefficients (β) less than 20% reveals an absence of confounder. Interaction for the main effect model was also be checked and partial likelihood ratio test result with p-value > 0.05 and Variance inflation factor less than 10 indicating the non-existence of multi-collinearity among the independent variables.

The multivariable binary logistic regression model was used to identify the independent factors associated with long-term unmet supportive care needs. The summary measures of estimated

crude (COR) and adjusted odds ratios (AOR) with 95% confidence interval were presented and P-value less than 0.05 was used to declare statistical significance and goodness of fit of the model was assessed by using Hosmer and Lemeshow goodness of fit test. Finally, the results were presented in statements, tables, and figures.

Results

Sociodemographic characteristics

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

Table 1: Sociodemographic characteristics of adult stroke survivors receiving routine follow-up 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

Abbreviations: [a]NGO: Non-governmental organization. USD: United States Dollar. [#]**others:** Afar, Southern Nations, nationalities and peoples regional state. Others[w]: Student, and daily laborer.

Clinical characteristics of participants

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

Table 2: Clinical characteristics of adult stroke survivors receiving routine follow-up services 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

Abbreviation: [¥]mRS: Modified Rankin Scale

Physiotherapy service utilization

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

The magnitude of unmet supportive care needs

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

Table 3: The magnitude of unmet supportive care needs among adult stroke survivors receiving 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)

Factors associated with Long Term Unmet needs

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

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

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

Table 4: Factors associated with long term unmet supportive care needs among adult stroke survivors, Addis Ababa, Ethiopia, 2020 (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	0.002	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	**0.004**	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	**0.001**	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****

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

Discussion

Background

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

Socio-demographic Characteristics

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

Clinical Characteristics

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

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

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

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

The magnitude of unmet needs

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

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

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

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

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

Limitations of this study

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

Conclusions

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

Acknowledgements: The authors thank all adult stroke survivors who took the time to complete the survey.

Funding: This research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests: None declared.

Contributors: EGT: project inception, management, and clinical input. MG, YMY: project inception, questionnaire design. SG and ZHG conducted the statistical analysis and interpreted the findings. All contributed to this manuscript and approved the final draft.

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

Patient consent for publication: Not required.

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

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

References

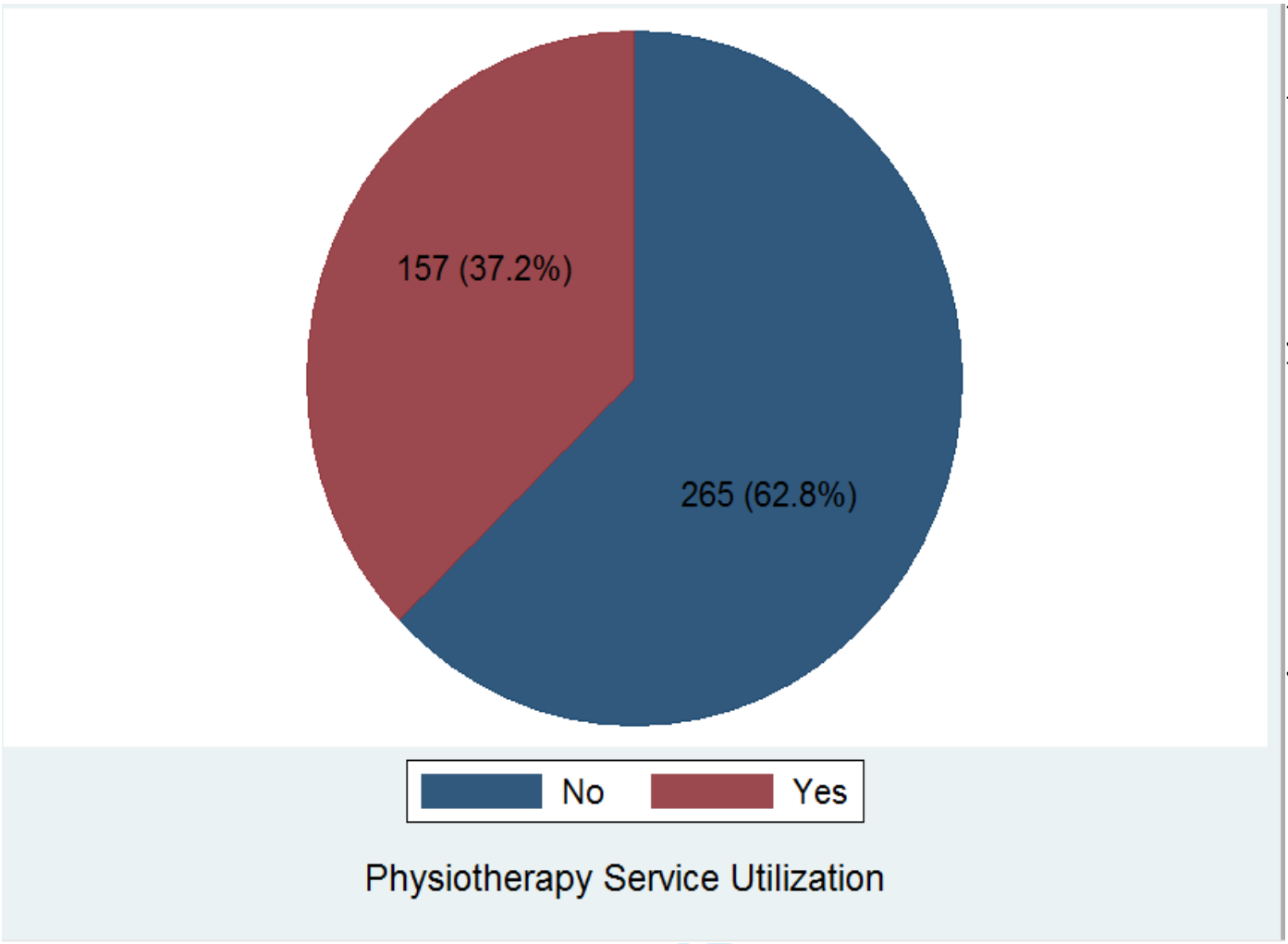
1. GBD 2017 Disease and Injury Incidence and Prevalence Collaborators. Global, regional, and national incidence, prevalence, and years lived with disability for 354 diseases and injuries for 195 countries and territories, 1990–2017: a systematic analysis for the Global Burden of Disease Study 2017. *Lancet*. 2018; 390(1):1789–858.
2. Strong K, Mathers C, Bonita R. Preventing stroke: saving lives around the world. *Lancet Neurol.* 2007; 6(2):182–187.
3. Association S. Together We Can Conquer Stroke: Stroke Association Strategy 2015 to 2018. 2013; (November): 1–23.
4. Kelley AS, Morrison RS. Palliative Care for the Seriously Ill. *N Engl J Med*. 2015 Aug 20; 373(8): 747–55.
5. World Health Organization Regional Office for Africa. Health situation analysis of the African region. Atlas Afr Health Stat 2012. 2012; 1–105. Available from: https://www.afro.who.int/publications/atlas-african-health-statistics-2012-health-situation-analysis-african-region.
6. Walker R, Whiting D, Unwin N, Mugusi F, Swai M, Aris E, et al. Stroke incidence in rural and urban Tanzania: A prospective, community-based study. *Lancet Neurol*. 2010;9(8):786–92.
7. Okoye EC, Awhen PA, Akosile CO, Maruf FA, Iheukwumere N, Egwuonwu AV. Caregiver-proxy reliability of the Igbo-culture adapted Maleka stroke community reintegration measure: A validation study. *Top Stroke Rehabil*. 2017; 24(6): 422–7.
8. Sarfo FS, Akassi J, Kyem G, Adamu S, Awuah D, Kantanka OS, et al. Long-Term Outcomes of Stroke in a Ghanaian Outpatient Clinic. *J Stroke Cerebrovasc Dis*. 2018; 27(4): 1090–9.
9. Sarfo FS, Adamu S, Awuah D, Sarfo-Kantanka O, Ovbiagele B. Potential role of tele-rehabilitation to address barriers to implementation of physical therapy among West African stroke survivors: A cross-sectional survey. *J Neurol Sci*. 2017 Oct 15; 381: 203–8.
10. Abrahamson V, Wilson PM. How unmet are unmet needs post-stroke? A policy analysis of the six-month review. *BMC Health Serv Res*. 2019 Jul 12; 19(1): 480-9.
11. Center for disease control and prevention. Epi info, a data base and statistics program for public health professionals. Atlanta, Georgia, USA: Center for disease control and prevention; 2018.

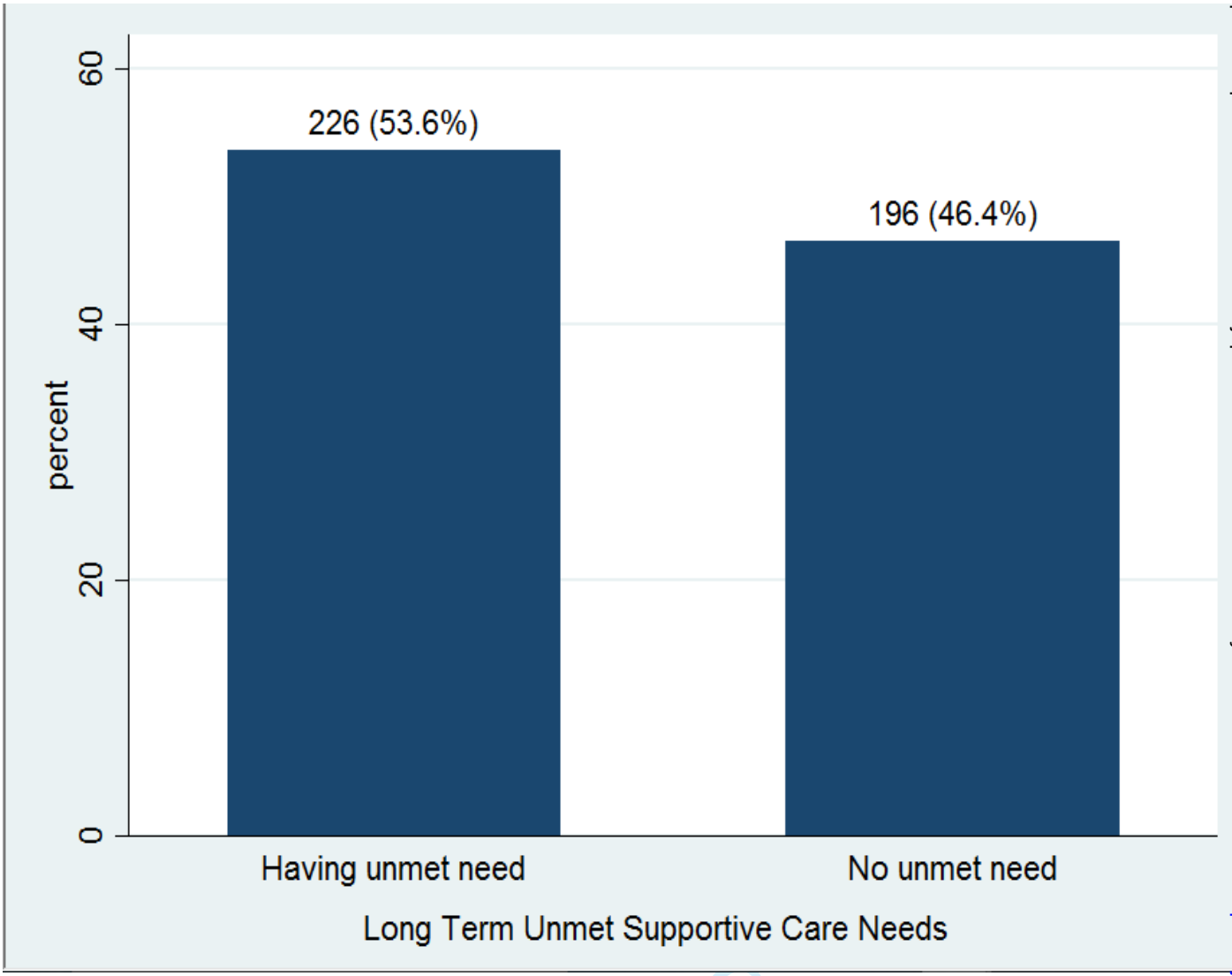
12. Banks JL, Marotta CA. Outcomes validity and reliability of the modified Rankin scale: implications for stroke clinical trials: a literature review and synthesis. *Stroke*. 2007 Mar; 38(3): 1091–6.
13. LoTS care LUNS study team. Validation of the longer-term unmet needs after stroke (LUNS) monitoring tool: a multi-center study. *Clin Rehabil*. 2013 Nov; 27 (11): 1020–8.
14. Murray CD, Harrison B. The meaning and experience of being a stroke survivor: an interpretative phenomenological analysis. *Disabil Rehabil*. 2004 Jul 8; 26(13): 808–16.
15. Hotter B, Padberg I, Liebenau A, Knispel P, Heel S, Steube D, et al. Identifying unmet needs in long-term stroke care using in-depth assessment and the Post-Stroke Checklist – The Managing Aftercare for Stroke (MAS-I) study. *Eur Stroke J*. 2018; 3(3): 237–45.
16. StataCorp. Stata Statistical Software: Release 14. College Station, Texas, USA: StataCorp LLC; 2017.
17. David WH, Stanley L. Applied Logistic regression. Second edition. Massachusetts, USA: Wiley series in probability and statistics; 2000. 95 p.
18. Deresse B, Shaweno D. Epidemiology and in-hospital outcome of stroke in South Ethiopia. *J Neurol Sci*. 2015 Aug 15;355(1–2):138–42.
19. Benjamin EJ, Virani SS, Callaway CW, Chamberlain AM, Chang AR, Cheng S, et al. Heart disease and stroke statistics - 2018 update: A report from the American Heart Association. Circulation. 2018;137(12).
20. Lehnerer S, Hotter B, Padberg I, Knispel P, Remstedt D, Liebenau A, et al. Social work support and unmet social needs in life after stroke: A cross-sectional exploratory study. *BMC Neurol.* 2019;19(1):1–10.
21. Chen T, Zhang B, Deng Y, Fan JC, Zhang L, Song F. Long-Term unmet needs after stroke: Systematic review of evidence from survey studies. *BMJ Open*. 2019; 9(5): e028137.
22. Murgo M, Cavanagh K, Latham S. Health Related Quality of Life and support needs for sub-arachnoid haemorrhage survivors in New South Wales Australia. *Aust Crit Care*. 2016 Aug 1; 29(3): 146–50.
23. McCurley JL, Funes CJ, Zale EL, Lin A, Jacobo M, Jacobs JM, et al. Preventing Chronic Emotional Distress in Stroke Survivors and Their Informal Caregivers. *Neurocrit Care*. 2019 Jun; 30 (3): 581-9.

Figure legends

Figure 1: Magnitude of Physiotherapy service utilization among adult stroke survivors receiving routine follow-up services Addis Ababa, Ethiopia, 2020 (n=422).

Figure 2: Magnitude of Long Term Unmet Supportive Care Needs among adult stroke survivors receiving routine follow-up services Addis Ababa, Ethiopia, 2020 (n=422).





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

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

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2021-053579.R1
Article Type:	Original research
Date Submitted by the Author:	25-Oct-2021
Complete List of Authors:	Tamrat, Edna; Addis Ababa University College of Health Sciences, Department of Preventive Medicine ; Gufue , Zenawi; Adigrat University College of Health Sciences, Department of Public Health Getachew, Sefonias; Addis Ababa University, Department of Preventive Medicine Yifru, Yared; Addis Ababa University College of Health Sciences, Department of Neurology, Faculty of Medicine Gizaw , Muluken ; Addis Ababa University College of Health Sciences, Department of Preventive Medicine, School of Public Health
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

I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our licence.

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which Creative Commons licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

Original research

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

Edna Gebremichael Tamrat[1*], Zenawi Hagos Gufue[3], Sefonias Getachew[1], Yared Mamushet Yifru[2], Muluken Gizaw[1]

[1*]Department of Preventive Medicine, School of Public Health, Addis Ababa University.

[2]Department of Neurology, Faculty of Medicine, Addis Ababa University

[3]Department of Public Health, College of Medicine and Health Sciences, Adigrat University

Corresponding Author

[1*]Edna Gebremichael Tamrat (BSc, MPH)

Department of Preventive Medicine, School of Public Health, Addis Ababa University.

Email: ednagtamrat@gmail.com, Phone Number: +251 920 19 74 36

P.O.BOX: 9086, website: http://www.aau.edu.et/

Addis Ababa, Ethiopia

Abstract

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

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

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

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

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

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

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

Strengths and limitations of this study

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

Introduction

Globally, stroke is the second leading cause of death following ischemic heart disease, being responsible for 8.76 million deaths, and taking lives every five seconds. Stroke is the second most common cause of adult disability (4.6%) of the global Disability Adjusted Life Years (DALYs).[1] Without significant interventions, the global stroke mortality is estimated to rise to 7.8 million deaths per year by the end of 2030.[2] The global economic cost of adult stroke is more than 25 billion dollars per year.[3]

Supportive care is defined as, rendering essential services that satisfy stroke patients' physical, psychological, social, informational, and spiritual needs over the entire illness trajectory. Supportive care is an essential buffering component of stroke survivors that helps to regain

emotional stability, social adjustment, cognitive function, body image, future perspective, and physical recovery.[4]

In Sub-Saharan Africa (SSA), stroke primarily affects the young and productive segment of the population.[5,6] The development of appropriate service provision is limited by the lack of vigorous estimates of longer-term outcomes after stroke and the prevalence of stroke survivors in SSA was reported to be 14.6/1,000 people.[7] High burden of uncontrolled vascular risk factors due to low screening and treatment modalities, uncoordinated, and fragmentary acute stroke care, and limited rehabilitation services were described as factors associated with poor prognosis after Stroke.[5,7] The increase in the magnitude of Stroke, thus calls the urge to identify their unmet needs to accelerate their recovery.[8]

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

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

Methods and Materials

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

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

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

Sample size determination and sampling technique

The sample size was determined by applying a single population proportion formula using Epi Info version 7.2.4.0 software[11], with the assumptions of a 95% level of confidence, a 5% margin of error. Since we couldn't find any previous studies conducted in Africa to determine the longer-term unmet supportive care needs among adult stroke survivors, the sample size was calculated by taking the largest sample size to detect a statistically significant difference. Accordingly, the percent of stroke survivors who have long-term unmet supportive care needs

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

Sampling procedure

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

Data collection instrument

A pre-tested structured interviewer-administered questionnaire, which contains the socio-demographic, clinical, neurological factors, and the Longer Term Unmet Supportive Care Needs (LUNs) questions, was used to collect the data. The interviewer-administered questionnaire was prepared in English then translated into the local language (Amharic) and re-translated back to English to maintain its consistency. The level of disability of the stroke survivors was measured by using the Modified Rankin Scale (mRS).[12]

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

Operational definitions

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

Supportive Care Needs: These includes physical relationships, managing money, accessible holidays, pain, driving, memory, information, employment, benefits, daily occupations, bladder control, mood, adaptations outside, diet, home help, moving house, transportation, adaptations inside, falling, mobility, blood pressure.[15]

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

Data processing, management, and analysis

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

The bivariate analysis was done to check the existence of crude association and to select candidate variables, those variables which are clinically important and having ($P < 0.25$) were included in the final model.[17] Confounding was checked, and percentage change in the regression coefficients (β) less than 20% reveals an absence of confounder. Interaction for the main effect model was also be checked and partial likelihood ratio test result with p-value > 0.05 and Variance inflation factor less than 10 indicating the non-existence of multi-collinearity among the independent variables.

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

Patient and public involvement

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

Results

Sociodemographic characteristics

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

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

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

Variables	Categories	Frequency	Percent (%)
Age, median (25th-75th), years		54.5 (43-62)	
Age (in years)	<45	112	26.5
	45-54	99	23.4
	55-64	118	28
	65-74	55	13
	75-84	34	8.1
	>85	4	1
Gender	Male	243	57.6
	Female	179	42.4
Residence	Urban	338	80.1
	Rural	84	19.9
Region	Addis Ababa	307	72.7
	Oromia	77	18.3
	Amhara	19	4.5
	Others#	19	4.5
Marital status	Married	282	66.8
	Never married	50	11.9
	Divorced	32	7.6
	Common law	58	13.7
Religion	Orthodox	323	76.5
	Protestant	45	10.7
	Catholic	39	9.2
	Muslim	15	3.6
Educational level	Unable to read and write	40	9.5
	Able to read and write	80	18.9
	Primary school completed	56	13.3
	Secondary school completed	101	23.9
	Diploma or degree	107	25.4
	Masters and above	38	9
Occupational status (n=419)	Farmer	59	14.1
	Government employee	138	32.9
	Trader	53	12.7
	NGO[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

Abbreviations: [a]NGO: Non-governmental organization. USD: United States Dollar. [#]**others:** Afar, Southern Nations, nationalities and peoples regional state. Others[w]: Student, and daily laborer.

Clinical characteristics of participants

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

Table 2: Clinical characteristics of adult stroke survivors receiving routine follow-up services 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

Abbreviation: [¥]mRS: Modified Rankin Scale

Physiotherapy service utilization

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

The magnitude of unmet supportive care needs

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

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

Longer-Term Unmet Supportive Care Needs (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)

Factors associated with Longer-Term Unmet needs

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

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

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

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

Patient profile	Categories	Longer-Term Supportive Care Needs		COR	P-value	AOR (95% CI)	P-value
		Having Unmet need	No unmet need				
Age (in years)	<45	63 (14.9)	49 (11.6)				**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	0.002	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	**0.004**	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	**0.001**	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****

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

Discussion

Background

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

Socio-demographic Characteristics

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

Clinical Characteristics

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

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

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

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

The magnitude of unmet needs

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

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

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

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

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

Limitations of this study

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

Conclusions

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

Acknowledgements: The authors thank all adult stroke survivors who took the time to complete the survey.

Funding: This research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests: None declared.

Contributors: EGT: project inception, management, statistical analysis and overall write up. YMY: project inception, questionnaire design. SG and ZHG conducted the statistical analysis and interpreted the findings, MG: project inception, questionnaire design and supervision. All contributed to this manuscript and approved the final draft.

Patient consent for publication: Not required.

Ethics approval: The study received approval from the institutional review board of the School of Public Health, Addis Ababa University (Ref: SPH/005/2020). Furthermore, the study received an ethical approval from both hospitals where the study was conducted before data collection was started. Consent was received from study participants after a clear explanation of the objectives, benefits and risks of

the study. The participants were also given the right to discontinue anytime if they don't feel like participating.

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

References

1. GBD 2017 Disease and Injury Incidence and Prevalence Collaborators. Global, regional, and national incidence, prevalence, and years lived with disability for 354 diseases and injuries for 195 countries and territories, 1990–2017: a systematic analysis for the Global Burden of Disease Study 2017. *Lancet*. 2018; 390(1):1789–858.
2. Strong K, Mathers C, Bonita R. Preventing stroke: saving lives around the world. *Lancet Neurol.* 2007; 6(2):182–187.
3. Association S. Together We Can Conquer Stroke: Stroke Association Strategy 2015 to 2018. 2013; (November): 1–23.
4. Kelley AS, Morrison RS. Palliative Care for the Seriously Ill. *N Engl J Med*. 2015 Aug 20; 373(8): 747–55.
5. World Health Organization Regional Office for Africa. Health situation analysis of the African region. Atlas Afr Health Stat 2012. 2012; 1–105. Available from: https://www.afro.who.int/publications/atlas-african-health-statistics-2012-health-situation-analysis-african-region.
6. Walker R, Whiting D, Unwin N, Mugusi F, Swai M, Aris E, et al. Stroke incidence in rural and urban Tanzania: A prospective, community-based study. *Lancet Neurol*. 2010;9(8):786–92.
7. Okoye EC, Awhen PA, Akosile CO, Maruf FA, Iheukwumere N, Egwuonwu AV. Caregiver-proxy reliability of the Igbo-culture adapted Maleka stroke community reintegration measure: A validation study. *Top Stroke Rehabil*. 2017; 24(6): 422–7.
8. Sarfo FS, Akassi J, Kyem G, Adamu S, Awuah D, Kantanka OS, et al. Long-Term Outcomes of Stroke in a Ghanaian Outpatient Clinic. *J Stroke Cerebrovasc Dis*. 2018; 27(4): 1090–9.

9. Sarfo FS, Adamu S, Awuah D, Sarfo-Kantanka O, Ovbiagele B. Potential role of tele-rehabilitation to address barriers to implementation of physical therapy among West African stroke survivors: A cross-sectional survey. *J Neurol Sci*. 2017 Oct 15; 381: 203–8.
10. Abrahamson V, Wilson PM. How unmet are unmet needs post-stroke? A policy analysis of the six-month review. *BMC Health Serv Res*. 2019 Jul 12; 19(1): 480-9.
11. Center for disease control and prevention. Epi info, a data base and statistics program for public health professionals. Atlanta, Georgia, USA: Center for disease control and prevention; 2018.
12. Banks JL, Marotta CA. Outcomes validity and reliability of the modified Rankin scale: implications for stroke clinical trials: a literature review and synthesis. *Stroke*. 2007 Mar; 38(3): 1091–6.
13. LoTS care LUNS study team. Validation of the longer-term unmet needs after stroke (LUNS) monitoring tool: a multi-center study. *Clin Rehabil*. 2013 Nov; 27 (11): 1020–8.
14. Murray CD, Harrison B. The meaning and experience of being a stroke survivor: an interpretative phenomenological analysis. *Disabil Rehabil*. 2004 Jul 8; 26(13): 808–16.
15. Hotter B, Padberg I, Liebenau A, Knispel P, Heel S, Steube D, et al. Identifying unmet needs in long-term stroke care using in-depth assessment and the Post-Stroke Checklist – The Managing Aftercare for Stroke (MAS-I) study. *Eur Stroke J*. 2018; 3(3): 237–45.
16. StataCorp. Stata Statistical Software: Release 14. College Station, Texas, USA: StataCorp LLC; 2017.
17. David WH, Stanley L. Applied Logistic regression. Second edition. Massachusetts, USA: Wiley series in probability and statistics; 2000. 95 p.
18. Deresse B, Shaweno D. Epidemiology and in-hospital outcome of stroke in South Ethiopia. *J Neurol Sci*. 2015 Aug 15;355(1–2):138–42.
19. Benjamin EJ, Virani SS, Callaway CW, Chamberlain AM, Chang AR, Cheng S, et al. Heart disease and stroke statistics - 2018 update: A report from the American Heart Association. Circulation. 2018;137(12).
20. Lehnerer S, Hotter B, Padberg I, Knispel P, Remstedt D, Liebenau A, et al. Social work support and unmet social needs in life after stroke: A cross-sectional exploratory study. *BMC Neurol.* 2019;19(1):1–10.

21. Chen T, Zhang B, Deng Y, Fan JC, Zhang L, Song F. Long-Term unmet needs after stroke: Systematic review of evidence from survey studies. *BMJ Open*. 2019; 9(5): e028137.

22. Murgo M, Cavanagh K, Latham S. Health Related Quality of Life and support needs for sub-arachnoid haemorrhage survivors in New South Wales Australia. *Aust Crit Care*. 2016 Aug 1; 29(3): 146–50.

23. McCurley JL, Funes CJ, Zale EL, Lin A, Jacobo M, Jacobs JM, et al. Preventing Chronic Emotional Distress in Stroke Survivors and Their Informal Caregivers. *Neurocrit Care*. 2019 Jun; 30 (3): 581-9.

Figure legends

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).

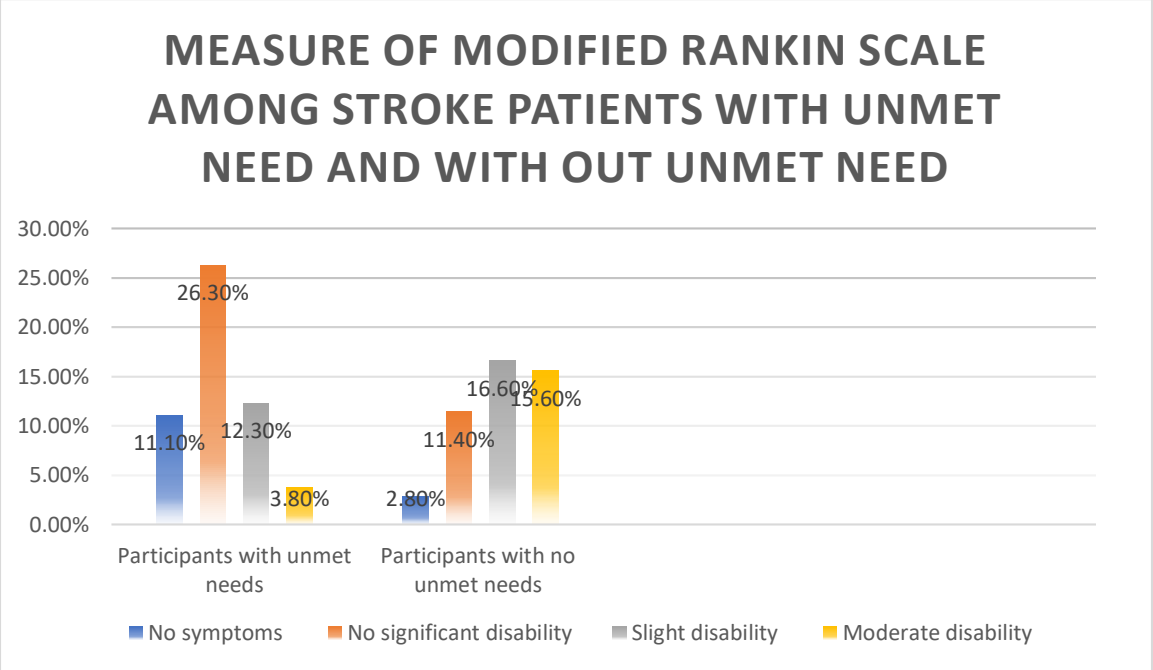


Figure 1: Score of Modified Rankin Scale among adult stroke survivors with and without Long Term Unmet Supportive Care Needs receiving routine follow-up services Addis Ababa, Ethiopia, 2020 (n=422).

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*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—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 *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants	5
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—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*) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed	6

		Cross-sectional study—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) *Cohort study*—Summarise follow-up time (eg, average and total amount)	
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time	
		Case-control study—Report numbers in each exposure category, or summary measures of exposure	
		Cross-sectional study—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

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2021-053579.R2
Article Type:	Original research
Date Submitted by the Author:	04-Jan-2022
Complete List of Authors:	Tamrat, Edna; Addis Ababa University College of Health Sciences, Department of Preventive Medicine ; Gufue , Zenawi; Adigrat University College of Health Sciences, Department of Public Health Getachew, Sefonias; Addis Ababa University, Department of Preventive Medicine Yifru, Yared; Addis Ababa University College of Health Sciences, Department of Neurology, Faculty of Medicine Gizaw , Muluken ; Addis Ababa University College of Health Sciences, Department of Preventive Medicine, School of Public Health
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

I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our licence.

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which Creative Commons licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

Original research

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

Edna Gebremichael Tamrat[1*], Zenawi Hagos Gufue[3], Sefonias Getachew[1], Yared Mamushet Yifru[2], Muluken Gizaw[1]

[1*]Department of Preventive Medicine, School of Public Health, Addis Ababa University.

[2]Department of Neurology, Faculty of Medicine, Addis Ababa University

[3]Department of Public Health, College of Medicine and Health Sciences, Adigrat University

Corresponding Author

[1*]Edna Gebremichael Tamrat (BSc, MPH)

Department of Preventive Medicine, School of Public Health, Addis Ababa University.

Email: ednagtamrat@gmail.com, Phone Number: +251 920 19 74 36

P.O.BOX: 9086, website: http://www.aau.edu.et/

Addis Ababa, Ethiopia

Abstract

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

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

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

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

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

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

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

Strengths and limitations of this study

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

Introduction

Globally, stroke is the second leading cause of death following ischemic heart disease, being responsible for 8.76 million deaths, and taking lives every five seconds. Stroke is the second most common cause of adult disability (4.6%) of the global Disability Adjusted Life Years (DALYs).[1] Without significant interventions, the global stroke mortality is estimated to rise to 7.8 million deaths per year by the end of 2030.[2] The global economic cost of adult stroke is more than 25 billion dollars per year.[3] (Figure 1)

Supportive care is defined as, rendering essential services that satisfy stroke patients' physical, psychological, social, informational, and spiritual needs over the entire illness trajectory. Supportive care is an essential buffering component of stroke survivors that helps to regain

emotional stability, social adjustment, cognitive function, body image, future perspective, and physical recovery.[4]

In Sub-Saharan Africa (SSA), stroke primarily affects the young and productive segment of the population.[5,6] The development of appropriate service provision is limited by the lack of vigorous estimates of longer-term outcomes after stroke and the prevalence of stroke survivors in SSA was reported to be 14.6/1,000 people.[7] High burden of uncontrolled vascular risk factors due to low screening and treatment modalities, uncoordinated, and fragmentary acute stroke care, and limited rehabilitation services were described as factors associated with poor prognosis after Stroke.[5,7] The increase in the magnitude of Stroke, thus calls the urge to identify their unmet needs to accelerate their recovery.[8]

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

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

Methods and Materials

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

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

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

Sample size determination and sampling technique

The sample size was determined by applying a single population proportion formula using Epi Info version 7.2.4.0 software[11], with the assumptions of a 95% level of confidence, a 5% margin of error. Since we couldn't find any previous studies conducted in Africa to determine the longer-term unmet supportive care needs among adult stroke survivors, the sample size was calculated by taking the largest sample size to detect a statistically significant difference. Accordingly, the percent of stroke survivors who have long-term unmet supportive care needs

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

Sampling procedure

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

Data collection instrument

A pre-tested structured interviewer-administered questionnaire, which contains the socio-demographic, clinical, neurological factors, and the Longer Term Unmet Supportive Care Needs (LUNs) questions, was used to collect the data. The interviewer-administered questionnaire was prepared in English then translated into the local language (Amharic) and re-translated back to English to maintain its consistency. The level of disability of the stroke survivors was measured by using the Modified Rankin Scale (mRS).[12]

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

Operational definitions

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

Supportive Care Needs: These includes physical relationships, managing money, accessible holidays, pain, driving, memory, information, employment, benefits, daily occupations, bladder control, mood, adaptations outside, diet, home help, moving house, transportation, adaptations inside, falling, mobility, blood pressure.[15]

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

Data processing, management, and analysis

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

The bivariate analysis was done to check the existence of crude association and to select candidate variables, those variables which are clinically important and having ($P < 0.25$) were included in the final model.[17] Confounding was checked, and percentage change in the regression coefficients (β) less than 20% reveals an absence of confounder. Interaction for the main effect model was also be checked and partial likelihood ratio test result with p-value > 0.05 and Variance inflation factor less than 10 indicating the non-existence of multi-collinearity among the independent variables.

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

Patient and public involvement

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

Results

Sociodemographic characteristics

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

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

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

Variables	Categories	Frequency	Percent (%)
Age, median (25th-75th), years		54.5 (43-62)	
Age (in years)	<45	112	26.5
	45-54	99	23.4
	55-64	118	28
	65-74	55	13
	75-84	34	8.1
	>85	4	1
Gender	Male	243	57.6
	Female	179	42.4
Residence	Urban	338	80.1
	Rural	84	19.9
Region	Addis Ababa	307	72.7
	Oromia	77	18.3
	Amhara	19	4.5
	Others#	19	4.5
Marital status	Married	282	66.8
	Never married	50	11.9
	Divorced	32	7.6
	Common law	58	13.7
Religion	Orthodox	323	76.5
	Protestant	45	10.7
	Catholic	39	9.2
	Muslim	15	3.6
Educational level	Unable to read and write	40	9.5
	Able to read and write	80	18.9
	Primary school completed	56	13.3
	Secondary school completed	101	23.9
	Diploma or degree	107	25.4
	Masters and above	38	9
Occupational status (n=419)	Farmer	59	14.1
	Government employee	138	32.9
	Trader	53	12.7
	NGO[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

Abbreviations: [a]NGO: Non-governmental organization. USD: United States Dollar. [#]**others:** Afar, Southern Nations, nationalities and peoples regional state. Others[w]: Student, and daily laborer.

Clinical characteristics of participants

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

Table 2: Clinical characteristics of adult stroke survivors receiving routine follow-up services 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

Abbreviation: [¥]mRS: Modified Rankin Scale

Physiotherapy service utilization

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

The magnitude of unmet supportive care needs

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

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

Longer-Term Unmet Supportive Care Needs (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)

Factors associated with Longer-Term Unmet needs

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

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

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

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

Patient profile	Categories	Longer-Term Supportive Care Needs		COR	P-value	AOR (95% CI)	P-value
		Having Unmet need	No unmet need				
Age (in years)	<45	63 (14.9)	49 (11.6)				**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	0.002	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	**0.004**	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	**0.001**	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****

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

Discussion

Background

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

Socio-demographic Characteristics

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

Clinical Characteristics

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

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

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

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

The magnitude of unmet needs

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

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

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

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

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

Limitations of this study

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

as the tool has never been used in Ethiopia. Acknowledging these potential limitations we hope that this finding can serve as baseline information for further research.

Conclusions

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

Acknowledgements: The authors thank all adult stroke survivors who took the time to complete the survey.

Funding: This research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests: None declared.

Contributors: EGT: project inception, management, statistical analysis and overall write up. YMY: project inception, questionnaire design. SG and ZHG conducted the statistical analysis and interpreted the findings, MG: project inception, questionnaire design and supervision. All contributed to this manuscript and approved the final draft.

Patient consent for publication: Not required.

Ethics approval: The study received approval from the institutional review board of the School of Public Health, Addis Ababa University (Ref: SPH/005/2020). Furthermore, the study received an ethical approval from both hospitals where the study was conducted before data collection was started. Consent was received from study participants after a clear explanation of the

objectives, benefits and risks of the study. The participants were also given the right to discontinue anytime if they don't feel like participating.

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

References

1. GBD 2017 Disease and Injury Incidence and Prevalence Collaborators. Global, regional, and national incidence, prevalence, and years lived with disability for 354 diseases and injuries for 195 countries and territories, 1990–2017: a systematic analysis for the Global Burden of Disease Study 2017. *Lancet*. 2018; 390(1):1789–858.
2. Strong K, Mathers C, Bonita R. Preventing stroke: saving lives around the world. *Lancet Neurol.* 2007; 6(2):182–187.
3. Association S. Together We Can Conquer Stroke: Stroke Association Strategy 2015 to 2018. 2013; (November): 1–23.
4. Kelley AS, Morrison RS. Palliative Care for the Seriously Ill. *N Engl J Med*. 2015 Aug 20; 373(8): 747–55.
5. World Health Organization Regional Office for Africa. Health situation analysis of the African region. Atlas Afr Health Stat 2012. 2012; 1–105. Available from: https://www.afro.who.int/publications/atlas-african-health-statistics-2012-health-situation-analysis-african-region.
6. Walker R, Whiting D, Unwin N, Mugusi F, Swai M, Aris E, et al. Stroke incidence in rural and urban Tanzania: A prospective, community-based study. *Lancet Neurol*. 2010;9(8):786–92.

7. Okoye EC, Awhen PA, Akosile CO, Maruf FA, Iheukwumere N, Egwuonwu AV. Caregiver-proxy reliability of the Igbo-culture adapted Maleka stroke community reintegration measure: A validation study. *Top Stroke Rehabil*. 2017; 24(6): 422–7.
8. Sarfo FS, Akassi J, Kyem G, Adamu S, Awuah D, Kantanka OS, et al. Long-Term Outcomes of Stroke in a Ghanaian Outpatient Clinic. *J Stroke Cerebrovasc Dis*. 2018; 27(4): 1090–9.
9. Sarfo FS, Adamu S, Awuah D, Sarfo-Kantanka O, Ovbiagele B. Potential role of tele-rehabilitation to address barriers to implementation of physical therapy among West African stroke survivors: A cross-sectional survey. *J Neurol Sci*. 2017 Oct 15; 381: 203–8.
10. Abrahamson V, Wilson PM. How unmet are unmet needs post-stroke? A policy analysis of the six-month review. *BMC Health Serv Res*. 2019 Jul 12; 19(1): 480-9.
11. Center for disease control and prevention. Epi info, a data base and statistics program for public health professionals. Atlanta, Georgia, USA: Center for disease control and prevention; 2018.
12. Banks JL, Marotta CA. Outcomes validity and reliability of the modified Rankin scale: implications for stroke clinical trials: a literature review and synthesis. *Stroke*. 2007 Mar; 38(3): 1091–6.
13. LoTS care LUNS study team. Validation of the longer-term unmet needs after stroke (LUNS) monitoring tool: a multi-center study. *Clin Rehabil*. 2013 Nov; 27 (11): 1020–8.
14. Murray CD, Harrison B. The meaning and experience of being a stroke survivor: an interpretative phenomenological analysis. *Disabil Rehabil*. 2004 Jul 8; 26(13): 808–16.
15. Hotter B, Padberg I, Liebenau A, Knispel P, Heel S, Steube D, et al. Identifying unmet needs in long-term stroke care using in-depth assessment and the Post-Stroke Checklist – The Managing Aftercare for Stroke (MAS-I) study. *Eur Stroke J*. 2018; 3(3): 237–45.
16. StataCorp. Stata Statistical Software: Release 14. College Station, Texas, USA: StataCorp LLC; 2017.
17. David WH, Stanley L. Applied Logistic regression. Second edition. Massachusetts, USA: Wiley series in probability and statistics; 2000. 95 p.
18. Deresse B, Shaweno D. Epidemiology and in-hospital outcome of stroke in South Ethiopia. *J Neurol Sci*. 2015 Aug 15;355(1–2):138–42.

19. Benjamin EJ, Virani SS, Callaway CW, Chamberlain AM, Chang AR, Cheng S, et al. Heart disease and stroke statistics - 2018 update: A report from the American Heart Association. Circulation. 2018;137(12).

20. Lehnerer S, Hotter B, Padberg I, Knispel P, Remstedt D, Liebenau A, et al. Social work support and unmet social needs in life after stroke: A cross-sectional exploratory study. *BMC Neurol.* 2019;19(1):1–10.

21. Chen T, Zhang B, Deng Y, Fan JC, Zhang L, Song F. Long-Term unmet needs after stroke: Systematic review of evidence from survey studies. *BMJ Open*. 2019; 9(5): e028137.

22. Murgo M, Cavanagh K, Latham S. Health Related Quality of Life and support needs for sub-arachnoid haemorrhage survivors in New South Wales Australia. *Aust Crit Care*. 2016 Aug 1; 29(3): 146–50.

23. McCurley JL, Funes CJ, Zale EL, Lin A, Jacobo M, Jacobs JM, et al. Preventing Chronic Emotional Distress in Stroke Survivors and Their Informal Caregivers. *Neurocrit Care*. 2019 Jun; 30 (3): 581-9.

Figure 1

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).

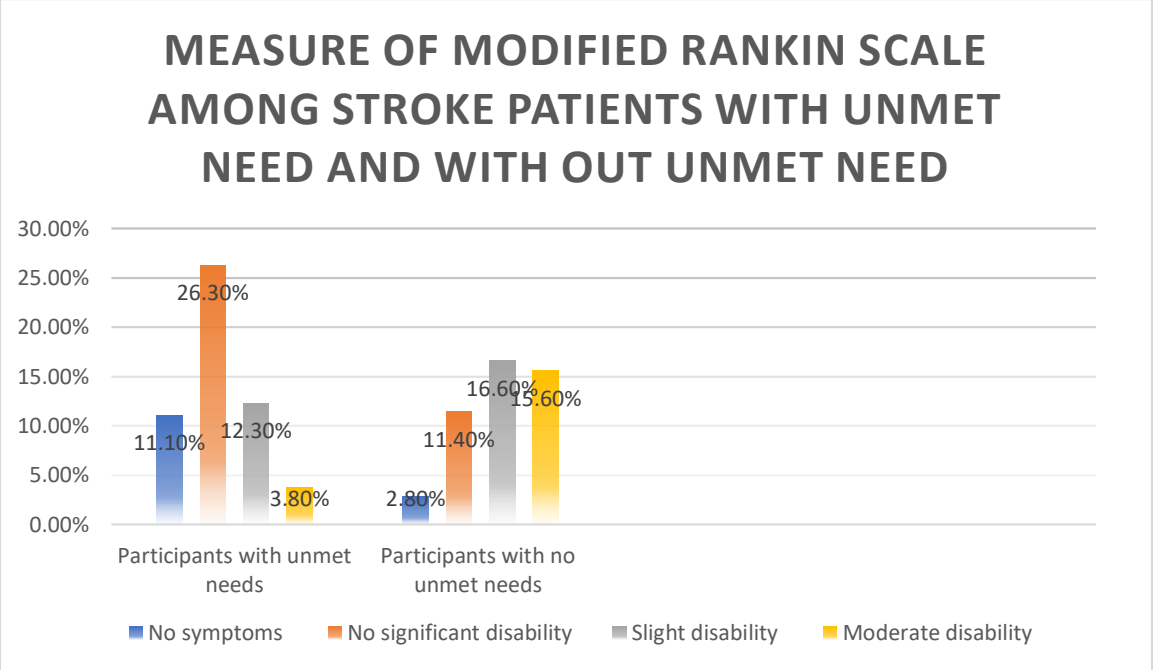


Figure 1: Score of Modified Rankin Scale among adult stroke survivors with and without Long Term Unmet Supportive Care Needs receiving routine follow-up services Addis Ababa, Ethiopia, 2020 (n=422).

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*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—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 *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants	5
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—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*) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed	6

		Cross-sectional study—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) *Cohort study*—Summarise follow-up time (eg, average and total amount)	
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time	
		Case-control study—Report numbers in each exposure category, or summary measures of exposure	
		Cross-sectional study—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.