Stroke-Related Knowledge and Lifestyle Behavior among Stroke Survivors

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Aims: Awareness of stroke symptoms and risk factors, and actions taken in order to reduce the risk of new stroke events, should be of great importance among stroke survivors. The aims of this study were to assess changes in stroke-related knowledge and lifestyle behavior among patients experiencing a cerebrovascular event, and to assess the agreement between the patients' self-reported diagnosis, and the discharge diagnosis. *Methods:* All patients discharged with a diagnosis of stroke or transient ischemic attack during a 1-year period, received postal survey questionnaires at 3 and 12 months after discharge. The questionnaires included questions about symptom knowledge, lifestyle behavior, and patients were asked to report on their diagnosis. *Results:* A total of 282 patients were included (mean age 71.8 years, 57.1% men). Self-reported symptom knowledge was increased at 3 months ($P < .001$), and this persisted at 12 months. There was a poor correlation ($r = .082$; $P = .171$) between increasing symptom knowledge and stated lifestyle behavior changes. In all, 63% of the respondents correctly identified their own cerebrovascular subtype. Thirty-seven percent had quit smoking after 12 months, 30% reported that they used less sugary items, and 26% used less fatty food after the cerebrovascular event. *Conclusions:* Stroke survivors reported increased stroke symptoms knowledge after 3 and 12 months. A proportion of patients made changes in lifestyle behavior. Only 2 out of 3 patients correctly identified their own cerebrovascular subtype, indicating room for improvement in clinical practice when informing and communicating with stroke and transient ischemic attack patients about their diagnosis.

Key Words: Acute stroke—cerebrovascular disease—knowledge—lifestyle behavior—self-reported diagnosis

Introduction

Stroke survivors are at high risk of recurrent stroke,[1,2] and mortality after a recurrent stroke is greater than after the first.[3] In addition to streamlining the acute stroke treatment, it is equally important to optimize secondary prevention in order to avoid recurrent strokes. Awareness of stroke symptoms and behavioral risk factors,[4,5] and actions taken in order to reduce the risk of recurrent stroke, should be of great importance to stroke survivors.

Studies on stroke-related knowledge and awareness of future stroke risk show diverging results,[6-8] although there is a trend toward poor knowledge, which leads to patients not engaging in the necessary preventive behaviors in order to reduce the risk of a recurrent stroke.[9-11]

The ability of patients to correctly identify their subdiagnosis poststroke has not been addressed in the

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literature. The accuracy of self-reporting has been evaluated,[12] but none have assessed the ability of discharged patients to correctly identify their cerebrovascular subtype.

The aim of this study was to assess stroke-related knowledge and changes in lifestyle behavior among patients experiencing a cerebrovascular event, and to determine whether adoption of a healthier lifestyle was correlated with knowledge of risk factors and preventive behaviors. Furthermore, we assessed the agreement between the patients' self-reported diagnosis and the discharge diagnosis.

Methods

This study was part of the prospective *Norwegian Stroke – Paths of Treatment* (NOR-SPOT) cohort, conducted at the Stroke Unit (SU), Department for Neurology, Akershus University Hospital. The hospital has a catchment area of about 500,000 inhabitants (about 10% of Norway's population), and serves a mixed urban and rural population. All patients discharged with a diagnosis of stroke (ischemic stroke or intracerebral hemorrhage) or transient ischemic attack (TIA) from the SU between February 15, 2012 and March 15, 2013, received postal survey questionnaires at 3 and 12 months after the time of discharge from the SU. The questionnaires included questions about symptom knowledge, lifestyle behavior, patient-related outcomes, and their social situation. Figure 1 shows the number of patients who received the questionnaires, and the number of patients who returned the questionnaires at 3 and 12 months.

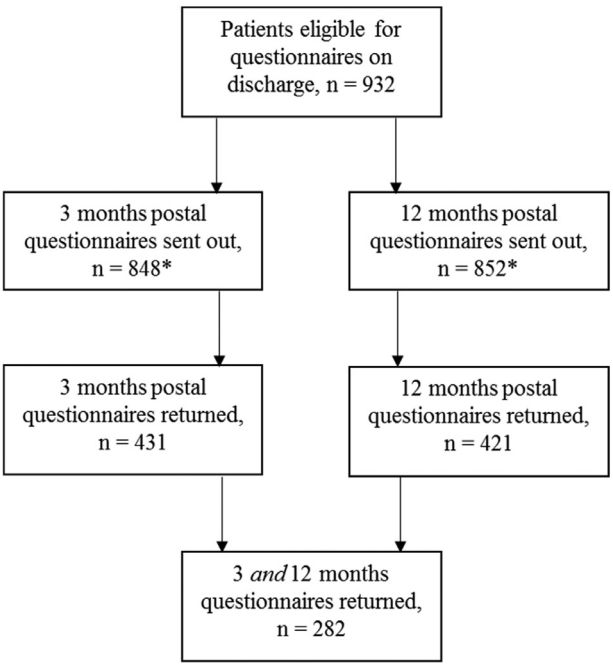

Figure 1. *Flow chart, the number of questionnaires sent out and returned. *n < 932 because of death, missing address data and late inclusion.*

In all, 431 patients returned the 3 months questionnaire and 421 patients the 12 months questionnaire. In the present study, patients who responded to *both* the 3 and 12 months questionnaire were included. The questionnaire included closed-ended questions on stroke symptom knowledge and life style behavior, and patients were asked to self-report their diagnosis.

Stroke symptom knowledge was tested by asking patients to state knowledge of the 3 symptoms face, arm/leg and speech corresponding to the Face Arm Speech Time (FAST) triad, and 2 additional, less common symptoms (dizziness and headache). Stroke risk factor knowledge was assessed by asking patients to state knowledge of the common risk factors smoking, diabetes, high cholesterol, older age, unhealthy diet, and alcohol. In the 3 months questionnaire, patients were asked about their knowledge of symptoms *before* the cerebrovascular event and at 3 months. Questions about symptom knowledge were asked again in the 12 months questionnaire. In addition, the questionnaire included questions about actions to take in the case of an acute stroke ("call the emergency medical services" (EMS) and "go directly to hospital"), and about changes in lifestyle behavior. The answer alternatives were "yes" and "no/unsure."

In the 12 months questionnaire, patients were also asked to report on their diagnosis (ischemic stroke, hemorrhagic stroke, TIA, and other diagnosis).

To assess whether adoption of a healthier lifestyle was more likely in stroke survivors with good or increased knowledge after stroke, knowledge of the 3 symptoms in the FAST triad (termed as the "FAST recognition score") were correlated to 5 self-reported lifestyle behavior actions; nonsmoking, diet change, use of less sugary items, use of less fatty food, and regular exercise (termed as the "Behavior score").

Statistics

Categorical variables are presented as absolute values and percentages. Paired *t* test and ANOVA were used to analyze changes in symptom knowledge. Spearman bivariate correlation was used to estimate the correlation between the FAST recognition score and the Behavior score.

Considering the hospital and the patients as 2 raters, the agreement between the self-diagnoses and the discharge diagnoses was summarized by means of Cohen's Kappa (κ). Since this question was only included in the 12 months questionnaire, answers from the respondents to this questionnaire (n = 421) were used for this analysis (Fig 1). Analyses were performed with IBM SPSS Statistics v. 23.

Ethics

The NOR-SPOT project was submitted for evaluation to the Regional Committee for Medical & Health Research

Ethics, and was exempted from evaluation as it was considered a quality assurance project. According to Norwegian law on medical research, projects not deviating from standard practice are classified as quality assurance projects, and ethical approval must be obtained from the local Privacy Ombudsman. The project was approved by the Privacy Ombudsman at Akershus University Hospital (reference number 2011-076). All respondents were informed about the project in the cover letter accompanying the questionnaires, and asked to return the questionnaires only if they consented to the information being used for research on stroke survivors' treatment paths and health related quality of life.

Results

A total of 282 patients were included in the study, with a mean age of 71.8 years (SD 11.6), and 161 (57.1%) were men. In all, 174 (61.7%) had suffered ischemic stroke, 25 (8.9%) intracerebral hemorrhage, and 83 (29.4%) TIA. The majority of patients (221; 78.3%) suffered from their first-ever cerebrovascular event.

Of 57 smokers, 21 (36.8%) had quit smoking after 12 months. Eighty-five patients (30.1%) reported that they used less sugary items, and 74 patients (26.2%) used less fatty food after the cerebrovascular event. Change in the proportion of patients who regularly exercised before and after the cerebrovascular event was nonsignificant ($P = .687$). At 12 months, 253 patients (89.7%) had visited their general practitioner (GP) for blood pressure control. The results are summarized in Table 1. Smoking was the most commonly identified risk factor (220; 78.0%). Of patients who were smokers on admission, 20 of 21 patients (95.2%) who quit smoking, named smoking as risk factor, compared to 27 of 36 patients (75.0%) who still smoked. Knowledge of stroke risk factors is listed in Table 1.

Table 1. *Lifestyle behavior and knowledge of risk factors after 12 months (n = 282)*

Lifestyle behavior	Frequency (%)
Previous smoker	88 (31.2)
Smoking before stroke	57 (20.2)
Stopped smoking after stroke	21/57 (36.8)
Diet change after stroke	45 (16.0)
Less sugary items after stroke	85 (30.1)
Less fatty food after stroke	74 (26.2)
Regularly exercise before stroke	83 (29.4)
Regularly exercise after stroke	91 (32.3)
Seen GP for BP control after stroke	253 (89.7)
Knowledge of risk factors	
Smoking	220 (78.0)
Diabetes	150 (53.5)
High cholesterol	205 (72.7)
Older age	176 (62.4)
Unhealthy diet	185 (65.6)
Alcohol	160 (56.7)

At 3 months, there was a significant increase in stroke symptom knowledge, and this persisted at 12 months (Table 2 and Fig 2). Knowledge on which actions to take was also significantly better poststroke, and further increased between 3 months and 12 months poststroke. Knowledge of all the 3 symptoms in the FAST triad increased from 40.8% before the cerebrovascular event to 70.6% at 12 months.

There was a poor correlation ($r = .082$; $P = .171$) between the FAST recognition score and the Behavior score, that is, between increasing symptom knowledge and lifestyle behavior changes (Fig 3).

Patients were asked to identify their diagnosis, and 421 answers were included in this part of the analysis. Among the TIA patients, 71.1% named the correct diagnosis; ischemic stroke patients 53.8%, while patients with intracerebral hemorrhage named their diagnosis correctly in 94.3% of cases (Table 3). In all, 62.7% of the respondents correctly identified their own cerebrovascular subtype. A total of 15.0% of the patients believed that they either had not had a cerebrovascular event (2.9%), or were unsure about their cerebrovascular subtype (12.1%). The remaining 22.3% chose the wrong cerebrovascular subtype. The agreement between the self-diagnoses and the discharge diagnoses was estimated at $\kappa = .44$ (95% CI = .38-.50), signifying *fair* to *moderate* agreement.[13] Restricting the analysis to only those who misidentified their cerebrovascular subtype κ was estimated to .57 (.50-.64); that is, moderate to substantial.

Discussion

The present study demonstrates a significant increase in knowledge of stroke symptoms after suffering a cerebrovascular event. In addition, 1 in 3 patients quit smoking and stated that they ate less sugary items. However, only 2 of 3 patients correctly identified their own cerebrovascular subtype.

Previous studies have reported somewhat diverging results on stroke symptom awareness, but systematic reviews have concluded with poor levels of knowledge about how to recognize and prevent stroke, and have underlined that there may be significant room to improve stroke knowledge among stroke survivors.[14,15] With this in mind, the results from the present study are to some extent encouraging, as there was a significant and persistent better knowledge of the most common stroke symptoms. Interestingly, the results for actions taken in case of stroke (call the EMS and go directly to the hospital) even improved further at 12 months compared to after 3 months. On the other hand, almost half of the patients with a final diagnosis of ischemic stroke specified other self-reported diagnoses. This may be related to insufficient information provided by physicians and other health care professionals during the index hospital admission or afterwards.

Table 2. *Stroke symptom and action knowledge (n = 282). Values expressed as n (%)*

	Before	3 months	12 months	*P* (*)	*P* (**)
Face	165 (58.5)	216 (76.6)	212 (75.2)	<.001	.643
Arm/leg	177 (62.8)	227 (80.5)	218 (77.3)	<.001	.265
Speech	166 (58.9)	226 (80.1)	225 (79.8)	<.001	.902
Dizziness	78 (27.7)	158 (56.0)	144 (51.1)	<.001	.194
Headache	68 (24.1)	143 (50.7)	139 (49.3)	<.001	.690
Call EMS	185 (65.6)	242 (85.8)	261 (92.6)	<.001	.003
Directly to hospital	52 (18.4)	93 (33.0)	140 (49.6)	<.001	<.001

Abbreviation: EMS, emergency medical services.
*Before versus 3 months.
**3 months versus 12 months.

In a comparable study,[16] only 14% of the patients could recall all the 3 symptoms in the FAST triad, while in our study 41% could recall all symptoms before the cerebrovascular event, increasing to about 70% after 3 and 12 months. In the study by Slark et al[16] 45% of the patients did not acknowledge that having a previous

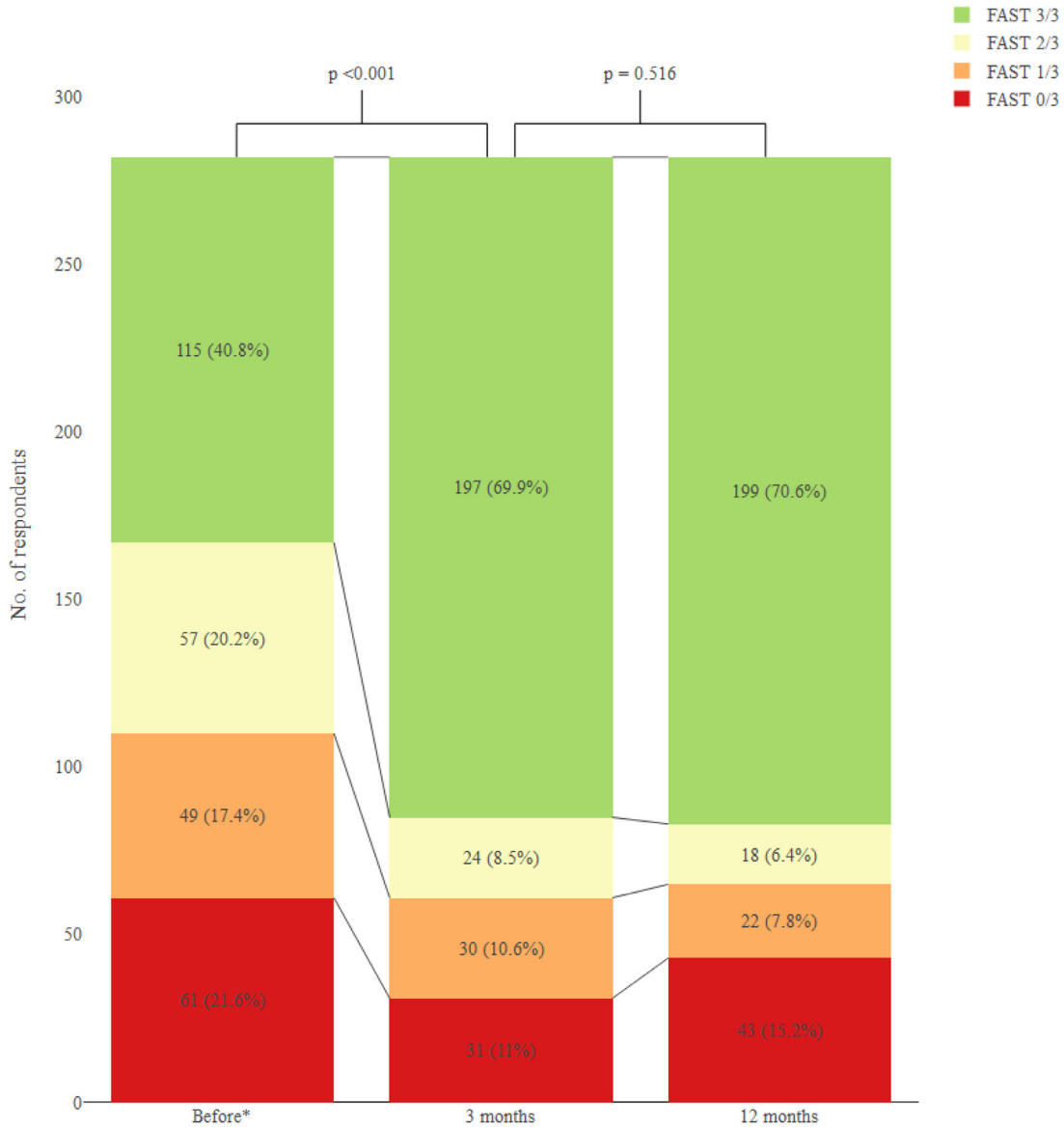

Figure 2. *Knowledge of the number of symptoms in the FAST triad (Face, Arm/leg, Speech; N = 282). Abbreviation: FAST, Face Arm Speech Time. *Before admission, reported in the 3 months questionnaire.*

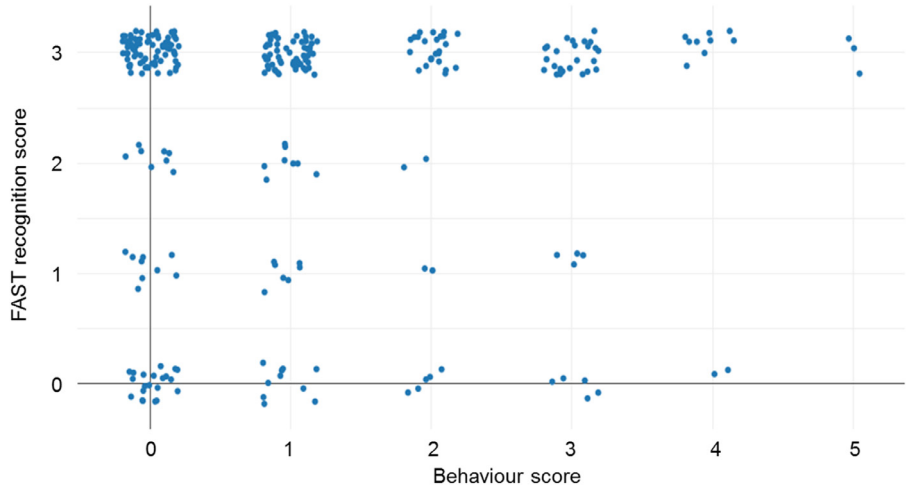

Figure 3. *Association between knowledge of the 3 symptoms in the FAST triad (FAST recognition score) and 5 lifestyle behavior actions; nonsmokers, diet change, less sugary items, less fatty food and regular exercise (Behavior score). Data collected 12 months after discharge from the stroke unit. Abbreviations: FAST, Face Arm Speech Time.*

stroke predisposed to future cardiovascular disease. It is reassuring that 93% of respondents correctly stated the appropriate action of notifying the EMS if suspected stroke, despite it being shown in previous studies that improved knowledge does not necessarily result in appropriate action when stroke is suspected.[17,18]

Smoking was the best-known risk factor, mentioned by 78%, and diabetes by 54%, corresponding well with the 75% and 48% in a previous survey.[10] Better knowledge of specific risk factors has been reported among those having the same risk factor.[19]

Although there are several studies on poststroke knowledge on symptoms and risk factors, few have reported on secondary prevention strategies in stroke survivors. Because of an expected ageing and increasing population in the next decades, with stroke figures expected to increase considerably, it is equally important to prevent new cerebrovascular events as to optimize the acute stroke treatment. Repeated, easily understandable information during the acute stroke and rehabilitation admission, along with concrete proposals for lifestyle behavior changes are needed in order to prevent recurrent strokes. In this study, the proportion of patients who stated that they regularly exercised after the cerebrovascular event was not significantly different to prestroke, in contrast to the study by Slark et al,[16] in which 40% of the patients reported that they exercised more poststroke. Even a moderate level of physical activity is associated with a risk reduction of cardiovascular disease.[20] In the same study,[16] 18% had quit smoking, while in our study 37% of the patients who smoked before the admission, quit after the cerebrovascular event.

Importantly, almost 90% of patients had visited their GP to control their blood pressure by 12 months after the cerebrovascular event. The GP has an essential role in secondary stroke prevention after discharge from the SU. In order to avoid a missing link between the SU and the GP, cooperation and mutual communication is important. In Norway and many other countries, the health care system is divided into Specialist health care services and Primary health care services, and cooperation is hampered by different organizational configurations and separate clinical

Table 3. *Hospital admission diagnosis versus self-reported diagnosis (n = 421). Data collected 12 months after discharge from the stroke unit*

	Discharge diagnosis			
Self-reported diagnosis	TIA	AIS	ICH	Total
TIA	**96 (71.1)**	57 (22.7)	0 (.0)	153 (36.3)
AIS	10 (7.4)	**135 (53.8)**	0 (.0)	145 (34.4)
ICH	3 (2.2)	24 (9.6)	**33 (94.3)**	60 (14.3)
Don't know	18 (13.3)	31 (12.4)	2 (5.7)	51 (12.1)
Other diagnosis	8 (5.9)	4 (1.6)	0 (.0)	12 (2.9)
Total	135 (32.1)	251 (59.6)	35 (8.3)	421 (100.0)

Counts (percentages). Correct match between self-reported and discharge diagnoses are marked in bold.
Abbreviations: AIS, acute ischemic stroke; ICH, intracerebral haemorrhage; TIA, transient ischemic attack.

data systems. Optimal secondary stroke prevention requires sufficient stroke-related knowledge, knowledge of cardiovascular risk factors, strategies to be able to change lifestyle behavior, but also supervision, follow-up, and motivation. Knowledge alone will not facilitate optimal management, and there is a need to set realistic goals and practice skills, which often requires supervision in order to create patient empowerment.

Interestingly, only about 63% of the respondents correctly identified their own cerebrovascular subtype, and 15% believed they either had not had a cerebrovascular event or were unsure about their cerebrovascular subtype. It is reasonable to assume that correct understanding of own diagnosis will contribute to increased awareness on the most important risk factors. We found that in patients with a final diagnosis of ischemic stroke and TIA, almost 1 in 2 and 1 in 3, respectively, reported wrong diagnoses. Among patients with ischemic strokes reporting wrong diagnosis, TIA was wrongly mentioned as the final diagnosis in about half of the patients. Almost 10% of the patients with ischemic stroke believed that they had suffered from ICH. Such a misperception may lead to poor compliance on antithrombotic treatment. In patients with ICH, in contrast, correct diagnosis was reported in 94%. Patients with very good recovery appear to have lesser knowledge of risk factors.[10] Accordingly, patients with TIA and mild strokes possibly attain less awareness of risk factors.

In most previous studies on self-reported stroke, participants have been asked to report a lifetime history of stroke, and the studies have been population-based. In a systematic review on the accuracy of self-reported stroke, the positive predictive value of self-reported stoke ranged from 22% to 87% and sensitivity from 36% to 98%.[12] As expected, the positive predictive value increased with stroke prevalence.[12] Some studies have investigated the accuracy of self-reported stroke compared to medical records,[21,22] but none has, to our knowledge, investigated cerebrovascular subtype.

It is important to highlight important limitations. This is a single-center study where the data were collected via a two-stage postal survey, with a modest response rate. From a previous publication on the 3 months questionnaire,[23] we know that our nonresponders were more morbid and more likely to reside in a nursing home, and since inclusion for the present study was based on response to *both* questionnaires, this bias carries over. The responder rate on the 3 months questionnaire was 50.8% (431 of 848). Of these patients, 402 remained alive or at a known address at the time of the 12 months questionnaire, giving a responder rate of 70.1% (282 of 402). In addition, 139 first-stage nonresponders returned the 12 months questionnaire, giving a total responder rate of 49.4% (421 of 852). There is therefore a clear risk of responder bias. We were not able to estimate associations between nonresponse and stroke knowledge since none of the collected baseline variables contained information on the knowledge of stroke.

The patients' symptoms on admission were not recorded. Importantly, patients with cerebrovascular disease will potentially have significant deficits, which could influence both the response rate and the results. Patients with TIA were included in this study, and will (by definition) not experience sequelae and may therefore be more reluctant to lifestyle behavior changes. One important limitation is that the knowledge of stroke symptoms and actions before the cerebrovascular event was recorded in the 3 months questionnaire. Recall bias may have occurred, as the patients were asked to state their prestroke knowledge 3 months *after* the admission, and patients may have overestimated their prestroke knowledge. However, we believe that, if the patients were asked to state their knowledge during the admission (or, theoretically, before the admission), the knowledge levels would have been even poorer. Selection bias may also have occurred, as it is reasonable to expect that patients that are more motivated and interested in stroke awareness more likely will return the questionnaires. In addition, the use of close-ended questions may overestimate the "true" knowledge, as opposite to open-ended questions, which may underestimate it. In this study, the knowledge of the 2 additional less common symptoms, dizziness and headache, was also significantly better at 3 and 12 months, which may be related to the use of closed-ended questions. Furthermore, the validity of self-reported answers about symptoms, risk factors and lifestyle behavior may be uncertain, as patients may interpret e.g. diet change, less sugary items and less fatty items differently. Unfortunately, questions about risk factor knowledge were not included in the questionnaire.

In conclusion, stroke survivors reported increased stroke symptoms knowledge after 3 months, and this increase sustained for 12 months. A proportion of patients stated that they made changes in lifestyle behavior. Only 2 out of 3 patients correctly identified their own cerebrovascular subtype, and there seems to room for improvement in clinical practice when informing and communicating with stroke and TIA patients about their diagnosis. More studies are needed to verify these findings.

Declaration of Competing Interest

All authors declare that they have no conflict of interest.

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