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## Health literacy is associated with less depression symptoms, higher perceived recovery, higher perceived participation, and walking ability one year after stroke – a cross-sectional study

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### ABSTRACT

**Introduction:** Life after stroke may entail several lifestyle changes and new routines. Hence, it is imperative for people with stroke to understand and make use of health information, i.e. to have sufficient health literacy. This study aimed to explore health literacy and its associations with outcomes at 12-months post-discharge regarding depression symptoms, walking ability, perceived stroke recovery, and perceived participation in people with stroke.

**Methods:** This was a cross-sectional study of a Swedish cohort. Data were collected at 12 months post-discharge using European Health Literacy Survey Questionnaire, the Hospital Anxiety and Depression Scale, the 10-m walk test, and the Stroke Impact Scale 3.0. Each outcome was then dichotomized into favorable versus unfavorable outcome. Logistic regression was performed to assess the association between health literacy and favorable outcomes.

**Results:** The participants,  $n = 108$ , were on average 72 years old, 60% had mild disability, 48% had a university/college degree, and 64% were men. At 12 months post-discharge, 9% of the participants had inadequate health literacy, 29% problematic health literacy, and 62% sufficient health literacy. Higher levels of health literacy were significantly associated with favorable outcomes relating to depression symptoms, walking ability, perceived stroke recovery, and perceived participation in models adjusted for age, sex, and education level.

**Conclusion:** The association between health literacy and mental, physical, and social functioning 12-months post-discharge suggests that health literacy is an important factor to consider in post-stroke rehabilitation. Longitudinal studies of health literacy in people with stroke are warranted to explore the underlying reasons for these associations.

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### KEYWORDS

Stroke; stroke recovery; post-stroke depression; health literacy; walking ability; cross-sectional study

## Introduction

Secondary prevention of stroke is crucial, as recurrent strokes account for about 21% of all strokes in Sweden<sup>1</sup> and about 23% in the USA.<sup>2</sup> Secondary stroke prevention includes managing modifiable risk factors such as hypertension, dyslipidemia, smoking, unhealthy diet, and physical inactivity.<sup>3</sup> Hence, for the individual patient, the life after stroke may entail several lifestyle changes and new routines such as medication management, rehabilitation, and healthcare follow-ups including information and recommendations from healthcare professionals. Consequently, for people with stroke, the ability to understand and to use health

information is important to prevent recurrent strokes and to regain functioning.

However, the consequences that follow a stroke such as cognitive and communicative impairments, post-stroke fatigue, and depression<sup>4</sup> can make the understanding of health information particularly challenging. The knowledge and competence that enables people to “access, understand, appraise, and use information and services in ways that promote and maintain good health” is defined by World Health Organization (WHO) as health literacy.<sup>5</sup> Health literacy depends not only on the individual's ability but equally important is the capacity of healthcare organizations to provide services that

support the patient's abilities.<sup>6</sup> After a stroke, providing health information and patient education are therefore important tasks for healthcare professionals.

Health literacy has, over the last few decades, received increasing attention, with calls for action in the cardiovascular area,<sup>7</sup> as it has become clear that low health literacy is associated with reduced adherence to medical advice and greater healthcare utilization in the general population.<sup>8</sup> Low health literacy is common: a cross-European study found that 47% of the general populations had low health literacy.<sup>9</sup> In a Danish population-based study, up to 20% perceived it difficult to understand health information well enough to know what to do.<sup>10</sup> Low health literacy may be more common among people with cardiovascular diseases than in the general population: persons diagnosed with a heart attack, coronary heart disease, or stroke had higher odds of having low health literacy than those without these diagnoses.<sup>11</sup> Among people with cardiovascular diseases, including people with stroke, a significant association was found between higher health literacy and higher levels of physical activity, healthier diet, and better self-reported health.<sup>12</sup> The risks associated with low health literacy are, hence, double, as it may increase the risk of having a disease and worsen the outcomes of the disease.

Despite the risks associated with low health literacy for people with cardiovascular disease, few studies have specifically focused on people with stroke. We have only been able to identify a handful of studies, of which all have been conducted in the USA. One study identified that 59% of the discharged patients with stroke had low health literacy at the time of discharge.<sup>13</sup> People with stroke who have low health literacy have lower understanding of their medications<sup>14</sup> and lower medication adherence.<sup>15</sup> Other studies showed that people with stroke who have low health literacy are more dependent in their activities of daily living<sup>16</sup> and have poorer self-reported health.<sup>17</sup>

These few studies indicate possible associations between health literacy and outcomes in people with stroke. However, more studies are needed to strengthen the knowledge base in this area, including associations with outcomes previously not studied. As stroke affects many areas, such as mental,

physical, and social functioning,<sup>1,4</sup> this study targets associations between health literacy and both measured and self-reported outcomes after stroke. The aim is to explore health literacy in a Swedish cohort 12 months post-discharge, and the associations between health literacy and depression symptoms, walking ability, perceived stroke recovery, and perceived participation

## Materials and methods

This cross-sectional study was carried out in the context of a prospective observational study of patients with stroke discharged from acute hospital care, with referral to rehabilitation in primary care, as previously described in detail.<sup>18,19</sup> The recruitment was conducted between 2016 and 2018 in Stockholm, Sweden. In Stockholm, patients with stroke receive care at stroke units. Thereafter, they are either referred directly to home with continued rehabilitation at home, to geriatric wards for continued care before rehabilitation at home, or to specialized rehabilitation units. Inclusion criteria for the prospective observational study were patients who were to be discharged from hospital (stroke units or geriatric wards) with referral to rehabilitation at home and who could provide informed consent. Eligible patients received oral and written information about the study and written informed consent was obtained. Baseline data was collected at hospitals. At 3- and 12 months after hospital discharge, data was collected during home visits using performance-based tests and questionnaires.

In the present study, all participants who took part in the 12-month follow-up, and who had completed the European Health Literacy Survey Questionnaire, were included.

The study was approved by the Regional Ethics Committee in Stockholm. The study conforms to the STROBE Guidelines.

## Data collection

The Swedish version of the European Health Literacy Survey Questionnaire<sup>20,21</sup> was used to assess health literacy. The European Health Literacy Survey Questionnaire comprised of 16 items focusing on four dimensions: ability to access/obtain health

information; ability to understand health information (not only in written form); ability to process/appraise health information; and ability to apply/use health information. The European Health Literacy Survey Questionnaire score on each item ranges from 0 to 16 and can be categorized into inadequate (0–8), problematic (9–12), and sufficient (13–16) health literacy.

Sociodemographic data included age, sex, and educational level (elementary, secondary, or university/college). The Modified Rankin Scale, with scores ranging from 0 (no disability) to 6 (death) was used to assess the degree of disability, categorized as mild (0–1), moderate (2–3), and severe (4–6) disability.<sup>22</sup>

### Outcome variables and categorization

The overall aim of the prospective observational study was to study patient outcomes in the care trajectory from hospital to continued rehabilitation at home. For the present study, we included variables that we hypothesized could have an association with health literacy.

*Depression symptoms* were assessed using the Hospital Anxiety and Depression Scale<sup>23</sup> that includes a depression subscale with seven items. Scores range from 0 (no symptoms) to 3 (maximum symptoms); and the maximum score is 21. We used a total cutoff of  $\geq 4$  to assess depression symptoms, as has been recommended for people with stroke.<sup>24</sup>

*Walking ability* was assessed with the 10-m walk test<sup>25</sup> and categorized as walking without aids or walking with aids/unable to walk.

*Perceived recovery* was rated by the participants on a visual analog scale of the Stroke Impact Scale ranging from 0 (no recovery) to 100 (full recovery). There is no recommended cutoff for the Stroke Impact Scale; however, a change of  $\geq 15$  points has been suggested as a clinically meaningful change.<sup>26</sup> We therefore used a categorization of 0 to 84 to indicate low participation and recovery, and  $\geq 85$  to indicate high participation and high recovery. *Perceived participation* was assessed using the Stroke Impact Scale 3.0,<sup>26</sup> domain participation. The domain includes nine statements and the score ranges from 0 (maximum perceived impact on participation) to 100 (no perceived impact).

### Statistical analysis

As few participants had inadequate health literacy, we did not use the categorizations of the European Health Literacy Survey Questionnaire in the regression analyses. Instead, we used the uncategorized scale of 0–16 to include and analyze all available information.

Quantile regression was used to assess the age, sex, and education level adjusted associations between the continuous outcome variables (participation, recovery, and depression) and health literacy, without transformation of the data.

The outcome variables depression, walking ability, perceived stroke recovery, and perceived participation were then dichotomized using the aforementioned cutoffs.

Logistic regression was conducted with the following models: Model A was adjusted for age and sex; Model B was adjusted for age, sex, and education level; Model C was adjusted for age, sex, education level, and depression. Stata (College Station, Texas) version 14.2 was used for all analyses.

### Results

Characteristics of the participants 12-months post stroke are shown in Table 1. The participants,  $n = 108$ , were on average 72 years old, and the majority had mild disability after stroke, a high educational level, and were predominantly men.

Of the participants, 9% had inadequate health literacy; 29% had problematic health literacy; and 62% had sufficient health literacy.

The results from quantile regression for the continuous variables are shown in Table 2. Higher levels of health literacy were significantly associated with lower levels of depression symptoms and higher levels of perceived recovery and perceived participation in all models, regardless of adjustments for age, sex, and education level.

The results from logistic regression models are shown in Table 3. Higher levels of health literacy were significantly associated with all dichotomous outcomes, namely depression symptoms, walking ability, perceived stroke recovery, and perceived participation in models adjusted for age, sex, and education level. Health literacy was also associated with perceived recovery and perceived participation after

**Table 1.** Characteristics of the included participants ( $n = 108$ ).

Variable	Number (%)
Women	39 (36)
Age (years, mean, SD)	72 ± 12
Degree of disability*	
mild	64 (60)
moderate	38 (35)
severe	5 (5)
Education level	
elementary	31 (29)
secondary	25 (23)
university/college	52 (48)
Health literacy level	
inadequate	10 (9)
problematic	31 (27)
sufficient	67 (62)
Depression	31 (27)
Walk without aids	88 (85)
High recovery	60 (56)
High participation	59 (55)

\*Data missing on degree of disability for one participant

**Table 2.** Quantile regression models showing the cross-sectional association between continuous variables of clinical outcomes and higher health literacy one year post stroke.

Outcome		Model A	Model B
Depression	Coefficient	-0.24*	-0.24*
	95% CI	-0.43 to -0.057	-0.42 to -0.046
Recovery	Coefficient	1.90*	1.79*
	95% CI	0.31–3.48	0.23–3.36
Participation	Coefficient	2.73**	3.19**
	95% CI	0.84–4.63	1.30–5.09

**Model A** was adjusted for age and sex; **Model B** was adjusted for age, sex, and education level. Statistical significance was indicated by: \* $p < 0.05$ ; \*\* $p < 0.01$ .

**Table 3.** Logistic regression models showing the cross-sectional association between clinical outcomes and higher health literacy one year post stroke.

Outcome		Model A	Model B	Model C
Depression	Odds ratio	0.81**	0.81**	-
	95% CI	0.70–0.94	0.70–0.94	
Walk without aids	Odds ratio	1.21*	1.21*	1.19
	95% CI	1.01–1.45	1.00–1.45	0.98–1.44
High recovery	Odds ratio	1.28**	1.28**	1.21*
	95% CI	1.09–1.50	1.09–1.50	1.02–1.42
High participation	Odds ratio	1.34**	1.34**	1.25*
	95% CI	1.13–1.59	1.13–1.59	1.05–1.48

**Model A** was adjusted for age and sex; **Model B** was adjusted for age, sex, and education level; **Model C** was adjusted for age, sex, education level, and depression.

\* $p < 0.05$ ; \*\* $p < 0.01$ .

adjustments for depression symptoms. When depression symptoms were added to the models, the association with walking ability was no longer significant.

## Discussion

This study is the first non-US study that explores the association between health literacy and outcomes

after stroke and the first that includes depression symptoms, perceived recovery, perceived participation, and walking ability as variables. The results showed that participants, 12-months post-discharge after stroke, had a high level of health literacy and that higher health literacy was significantly associated with more favorable outcomes.

The association between health literacy and outcomes remained significant in models adjusted for

education. Previous studies have identified an association between education level and health literacy.<sup>28</sup> In our study, however, participant education level did not impact the outcomes. This may indicate that health literacy is independently associated with a positive outcome and that all patients after stroke, regardless of education level, benefit from healthcare services that can strengthen their health literacy.

The level of health literacy in our sample was higher than in a US-based study of people with stroke.<sup>13</sup> Reasons for this difference might be that health literacy is context dependent,<sup>29</sup> that is, a person's health literacy may decrease due to illness, shock, and unfamiliarity with the healthcare services and system. The data in our sample was collected one-year post stroke, whereas the US study collected data directly post-discharge from hospital. As health literacy can be distributed and improved through interactions with social networks and healthcare professionals,<sup>27</sup> the participants in our study may, hence, have had more opportunities to engage in interactions that improved their abilities to obtain, understand, process, and apply health information.

Our study is consistent with the few studies previously conducted on health literacy after stroke in terms of an association between health literacy and physical functioning – in our study measured as walking ability, and in a previous study by using the Barthel Index.<sup>16</sup> This study also contributes with findings on the association with mental and social functioning, that is, depression symptoms, perceived stroke recovery, and perceived participation. When depression symptoms were added to models, the association between health literacy and walking ability was no longer significant, whereas perceived stroke recovery and perceived participation remained significant. Thus, health literacy, i.e. a patient's ability to access, understand, appraise, and apply health information is particularly important to consider for favorable outcomes in depression symptoms, perceived stroke recovery, and perceived participation after stroke. Our results concur with the findings by Aaby et al. showing an association between health literacy and an increase in physical and mental health status for people with cardiovascular disease.<sup>12</sup> As health literacy has been found to positively affect self-management in other populations,<sup>30,31</sup> one plausible explanation for the

associations is that high health literacy increased the individual's ability to engage in self-management activities in their stroke recovery process. However, the reason for these results needs to be further explored in longitudinal studies.

This study shows a possible association between health literacy and important outcomes after stroke, indicating that health literacy is important to consider when designing interventions post stroke. As health literacy is a complex phenomenon,<sup>32</sup> including both functional, communicative, and critical dimensions,<sup>33</sup> and being dynamic and context dependent,<sup>29</sup> a more person-centered approach is warranted that addresses both individual and contextual factors. Individual and contextual factors might be especially important in patients after stroke, as health literacy can be affected due to the sudden onset and potential cognitive and communicative barriers. Since health literacy can be improved through healthcare professionals' provision of information, effective communication, and structured education interventions,<sup>34</sup> there is need for person-centered health literacy interventions for people with stroke.

## Limitations

The present study was observational and had a cross-sectional design, which limits us from making causal claims. The results should therefore be interpreted with caution. We had a relatively small sample that limited the variables in the logistic regression models, for example cognition and aphasia; however, we were able to adjust for several relevant factors including depression and education level. As our inclusion criteria included persons who could provide informed consent, we have not data from people with severe aphasia and/or cognitive impairment. However, in the studied setting of care transitions from hospital to home, the majority of the patients have mild to moderate stroke. Most participants in our study had mild symptoms after stroke, and future larger studies should explore associations between health literacy and relevant clinical outcomes in people with more severe symptoms after stroke. It is possible that the respondents in our investigation had relatively higher health literacy than the average patient

with stroke which may have affected the statistical analysis, limiting the extrapolation of our findings to all people with stroke.

## Conclusion

Few studies have assessed the association between health literacy and outcomes after stroke. This study is the first non-US study that explores this association and the first that includes depression symptoms, perceived recovery, perceived participation, and walking ability as variables.

The association between health literacy and depression symptoms, perceived recovery, perceived participation, and walking ability 12 months post stroke suggests that health literacy could be an important factor to consider for stroke recovery and in post-stroke rehabilitation. As the area of health literacy in people with stroke is in its infancy, longitudinal and larger studies are warranted to explore the underlying reasons for these associations and other plausible variables of importance.

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## Disclosure statement

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## Author contributions

All authors meet the criteria for authorship.

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