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Research Article

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Health Literacy and Health Outcomes in Stroke Management: A Systematic Review and Evaluation of Available Measures

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Abstract

Low health literacy (HL) increases the risk of adverse stroke-related health outcomes. The aim of this review was to identify 1. what the quality and what the limitations to educational materials used to improve HL in stroke patients are 2. what the levels of HL among stroke patients and stroke survivors are, and 3. how HL and stroke literacy levels affect health-related behaviours and outcomes of stroke patients. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines were followed. 6 computerized databases and gray literature sources were searched: MEDLINE, OVID, EMBSE, CINAHL, Cochrane library, Web of Science, and Health and Psychosocial Instruments, and Google Scholar. Papers published in English between January 01, 2000 and August 01, 2020 were included. Five themes were identified across the 26 studies regarding the education and measurement of stroke with relevance to HL. This review concludes that current instruments used to improve HL in stroke are inadequate as they fail to provide a holistic assessment of health literacy, especially concerning stroke patients and stroke literacy. This review identified a paucity of literature on HL in relation to stroke management and outcomes. Therefore, the authors are in strong favour of future research prioritizing the development of effective tools to assess HL and develop best-practice guidelines for stroke education materials.

Keywords: Stroke, Health Literacy, Health Communications, Cardiovascular Diseases, Patient Care

Introduction

Cerebrovascular disease continues to be a significant cause of morbidity and mortality worldwide [1]. This pandemic poses significant challenges to healthcare systems and necessitates both preventive and treatment strategies. In Canada there are 62,000 strokes annually, making it the third leading cause of death and the tenth largest contributor to disability-adjusted life years [2,3]. The Canadian Health Literacy Expert Panel defines health literacy (HL) as "the degree to which people are able to access, understand, appraise and communicate information to engage with the demands of different health contexts in order to promote and maintain good health." (4) Evidence suggests that low levels of HL and inadequate presentation of healthcare information (e.g., use of complex terminology, not provided in a patient's preferred language) may limit patients' understanding of their health condition and increase risk of adverse outcomes [4-11]. In particular, a patient's HL greatly influences adherence to a treatment regimen[12,13]. Poor HL is a growing concern globally (4,8–10) as low levels of HL are associated with increased hospitalizations, emergency department visits, treatment non-adherence, and reduced self-management[4,8-10][1.12].

Some studies suggest that low HL among stroke patients results in poorer overall health and higher mortality rates [14,15]. However, there is no consensus in the literature regarding HL measures in stroke patients or the effects of HL on health outcomes in stroke patients [16,17]. This systematic review was performed, in order to provide more clarity on the quality of HL educational resources for stroke survivors, the limitations of existing tools used to assess HL, the HL status of this population, and the impact of HL on their health outcomes. We sought to answer the following questions: 1. What is the quality and what are limitations to educational materials used to improve HL in stroke patients 2. What are the levels of HL among stroke patients and stroke survivors, and 3. How do HL and stroke literacy levels affect health-related behaviours and outcomes of stroke patients.

Materials & Methods

This review is performed consistent with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Figure 1) [18,19]. We used standard Evidence-based Practice Center methods of dual review to determine article inclusion criteria.

Data Sources

NA developed a comprehensive search strategy, in consultation with the research team—NT, IP, GG, DH, aiming to address the key concepts underlying each research question. Seven computerized databases were searched: MEDLINE, OVID, EMBSE, CINAHL, Cochrane library, Web of Science, and Health and Psychosocial Instruments to identify articles regarding interventions specifically designed to mitigate the effects of low HL on stroke outcomes. We limited our search to English language papers published between January 01, 1980 and January 01, 2022. Since no MeSH terms specifically identify HL-related articles in stroke, we conducted keyword searches (access, understand, communicate, evaluate, use, health literacy, literacy, each key term combined with either stroke, stroke management, or hypertension). We also explored the gray literature through internet searches for any unpublished reports and examples of articles that considered both HL and stroke outcomes.

Study Selection

We included English language articles that labelled their research using the term health literacy or its components (e.g., access, understand, evaluate, communicate, or use of health information), within a relevant context, in their report. We included both qualitative and quantitative studies and observational studies, as well as expert-reviews. Our initial search yielded 335 articles, 4 of which were duplicates; 327 articles were screened and 144 were identified as potentially relevant references. NA and NT assessed the abstracts of the 166 articles against the inclusion criteria. Of the 166, 36 met the inclusion criteria and were retrieved as full-text articles. We incorporated the 36 appropriate articles in the full-text review (see Figure 1). Disagreements regarding inclusion of articles were resolved through discussion. In the event that agreement could not be reached, IP mediated further discussion until a consensus was reached. A data extraction form was developed and used independently by NA and NT to assess the 36 articles deemed appropriate for inclusion in the meta-analysis.

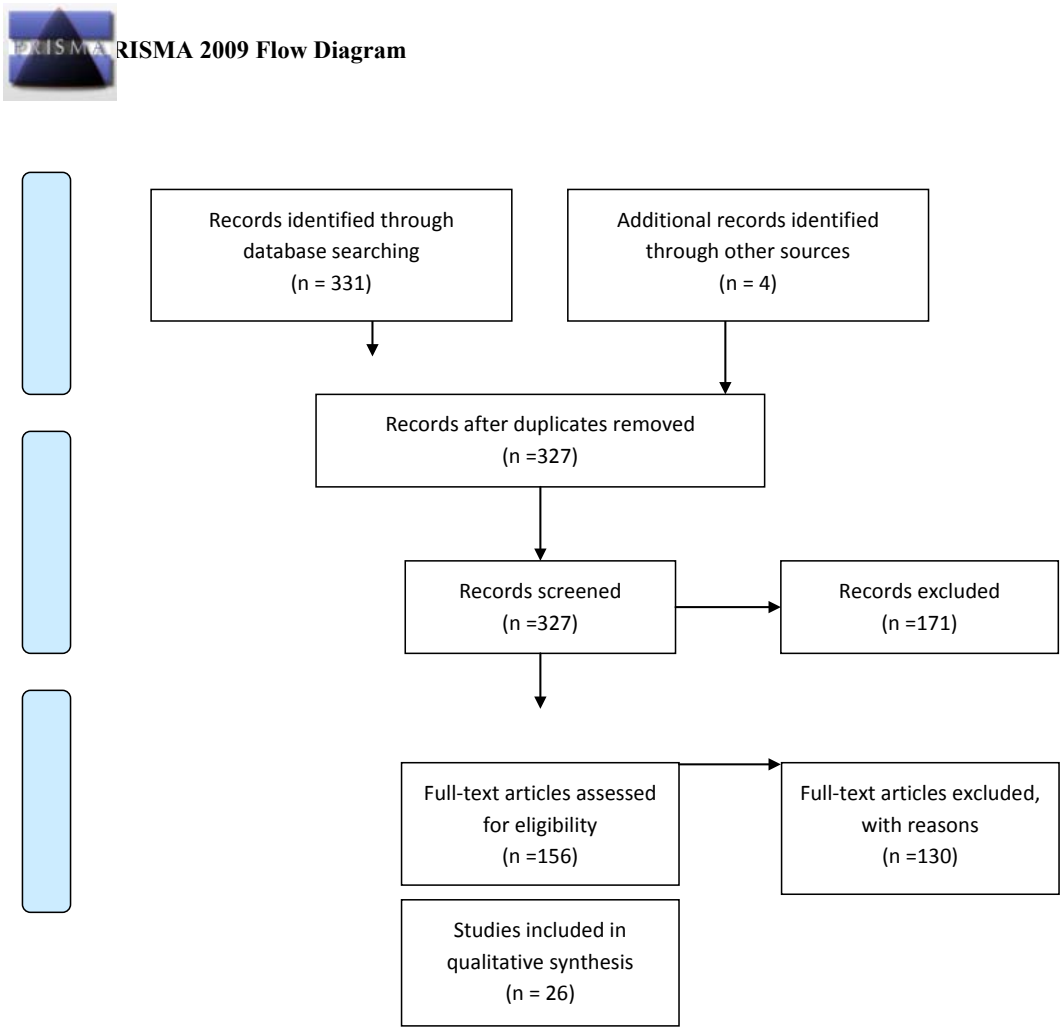

Figure I: PRISMA diagram showing the selection process of the literature.

PRISMA statement showing the selection process of the literature found for this analysis. Adapted from the PRISMA guidelines document.

Data Extraction and Data Analysis

NA and NT rated the quality of retained papers. Research quality aspects (e.g., blinding, potential study biases, and external/internal validity issues) were considered. Criteria assessing bias and confounding variables were followed. Disagreements were resolved through collaborative discussion. We conducted a qualitative review of the literature, with accepted data entered—and cross-referenced by NA—in a display matrix. The studies were imported into the Navigating Viewpoints, Images and Value Observed (NVivo) software version 12, a qualitative data analysis software [20]. All qualitative data from the aforementioned sources were included in the analysis. Data were coded, and thematic analysis was conducted to categorize and develop themes via constant comparison across nodes. We then systematically organized, compared, and categorized the similarities and differences between the various studies. Analysis subsequently rendered a number of key themes related to health literacy and stroke management that were applied during classification.

Results

Study Characteristics

Our evaluation revealed five common themes across the literature (see Figure 2), which are discussed in detail below. Of the 36 articles, 7 contributed to two themes (see Table 1). The first three themes discuss quality and limitations of existing educational materials for stroke patients, thereby addressing the first research question. The fourth theme relates to the second research question, discussing levels of HL in stroke patients and stroke survivors, and the fifth theme discusses how stroke literacy levels affect health-related behaviours and outcomes – addressing the third research question.

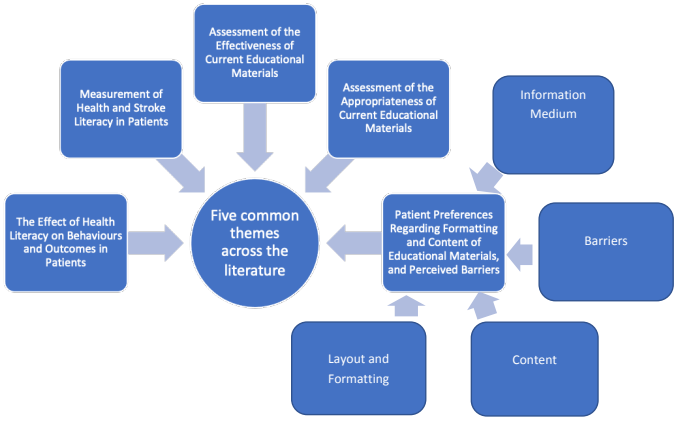

Figure 2: The 5 common themes found across the literature.

Table 1: Summary of the articles found.

MAJOR THEME OF STUDY	STUDY	PARTICIPANTS	DESIGN	RESULTS AND CONCLUSIONS	STRENGTHS AND LIMITATIONS
PATIENT PREFERENCES OF FORMATTING & CONTENT OF EDUCATIONAL MATERIALS, AND PERCEIVED BARRIERS	Schriner, 2011	30 non-aphasic stroke survivors at community-based education program.	Screened patients for low health literacy using NVS tool. Structured interview to discern media preference.	Two-thirds of sample at risk of limited health literacy. No statistically significant preference for media type.	The authors identify that he association between education and HL levels must be examined with caution as education has been determined a poor indicator of HL.
	Eames, et. Al. 2003	20 stroke survivors and 14 carers.	Questionnaire exploring perceptions of content and presentation of materials of increasing reading difficulty. Assessed reading ability of participants.	Majority felt information needs not met in hospital. Mean readability of materials (grade 9) higher than mean reading ability (grade 7-8). Decreased satisfaction with higher reading difficulty of material. Preference for simple language, large font, colour and diagrams to support text.	Qualitatively assessed both carer and patient's perceptions on stroke educational materials. Assessment of reading ability of participants was not adequately explained.

	Rose, et. Al. 2012	40 aphasic stroke survivors.	Quantitative questionnaire exploring preferences for printed material design.	Patients preferred 14-point font, Verdana font, 1.5 line spacing, and graphics to support text.	Assessed five preference domains for a comprehensive look at stroke survivor's preferences.
	Eames, et. Al. 2010	Initial interviews: 34 stroke survivors and 18 carers. Follow-up interviews: 27 stroke survivors and 16 carers.	Semi-structured qualitative interviews with patients and carers prior to and 3 months following discharge from acute stroke unit to assess perceived barriers to accessing and understanding stroke information.	Three categories of barriers identified: (1) limited availability/suitability of information, (2) barriers in hospital environment (ex. Continuity of care), and (3) patient and carer barriers (ex. Not enough time).	The use of qualitative content analysis from semi-structured interviews allows for a comprehensive look at the categories identified.
	Hoffmann, et. Al. 2006	57 stroke survivors and 12 carers in an acute stroke unit.	Semi-structured interview to assess informational needs. Reading ability of patients and readability of information was assessed.	Only 22.8% of patients and 41.7% of carers received written stroke information. Mean readability of material (grade 11) was higher than mean reading ability of patients (non-aphasic: grade 7-8; aphasic: grade 4-7).	Small sample size restricted the power of the calculation. The population studied was limited to one hospital and the results are therefore not generalizable.
	Donnellan, et al. 2013	8 stroke patients interviewed 3 months post-discharge.	Qualitative semi-structured interviews to explore patient experiences of stroke and care.	Patients requested more education and explanation of stroke from health professionals and believe this would facilitate adjustment to difficulties of stroke (ex. Lifestyle changes, new medications).	Random purposive sampling was used indicating lack of generalizability. The population is small (N=8) therefore the power of the calculation is restricted.
	Appalasamy et al., 2019	60 post-stroke patients in Malaysia were recruited as a part of a pilot study, and 54 in a parallel randomized control study	Pilot study gathered baseline data and medical information, and post measurement used video narratives on medication understanding and use self-efficacy and blood parameters were done for 3 months follow-up.	Over 85% of participants had adequate health literacy and reported exposure to stroke education. Qualitative phone interview with 8 of the participants found the video narratives method useful.	The results were not published after consideration in JMIR medical informatics. There was a low recruitment rate (38%) and the qualitative measures of the outcome were prone to biases.

	Martinez et a., 2016	145 stroke patients, 72 Hispanic identifying and 73 non-Hispanic White identifying recruited from the general community.	Authors performed prospective study of stroke patients from an academic Stroke Center in Arizona and surveyed members of the general community. Questionnaires included: the Duke Social Support Index (DSSI), the Multidimensional Health Locus of Control (MHLC) Scale, a stroke barriers questionnaire, and a Stroke Awareness Test.	Hispanic stroke patients reported greater barriers related to medical knowledge, medication adherence, and healthcare access ($p < 0.05$ for all)	Stroke severity was not included as a variable in the analysis, and the population was likely biased towards less severe strokes as the sampling population included only those able to complete the assessments.
APPROPRIATENESS OF CURRENT EDUCATIONAL MATERIAL	Eames, et al. 2003 Follow-up interviews: 27 stroke survivors and 16 carers.	Initial interviews: 34 stroke survivors and 18 carers.	Semi-structured qualitative interviews with patients and carers prior to and 3 months following discharge from acute stroke unit to assess perceived barriers to accessing and understanding stroke information.	Three categories of barriers identified: (1) limited availability/suitability of information, (2) barriers in hospital environment (ex. Continuity of care), and (3) patient and carer barriers (ex. Not enough time).	Qualitatively assessed both carer and patient's perceptions on stroke educational materials. Assessment of reading ability of participants was not adequately explained.
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	Supan, et al. 2010	None.	Assessed readability of written stroke education material available. Materials then edited to achieve target 6th grade reading level.	Majority of stroke education material written at grade 7 to college reading level. Some terms and concepts could not be simplified despite editing.	Readability was assessed using a score, no participants or qualitative perspectives regarding readability was obtained.

	Fitzsimmons, et al. 2010	None.	Assessed readability of the 100 highest ranked patient oriented stroke information web sites as identified by Google.	Information was found to be written at mean grade 10.2 reading level. Commercial websites were significantly easier to read, but still written at mean grade 8.6 reading level. No significant correlation between readability and search engine ranking.	Accessibility to and use of websites was not mentioned, and the classification of the rankings was performed by Google.
	Huang et al.	311 patient's data and item parameters were retrieved from a Rasch validation study.	Rasch analysis was used to identify whether or not the European Health Literacy Survey Questionnaire (HLS-EU-Q) is reliable.	The analysis showed that the 12-domain HLS-EU-Q demonstrated the best data–model fit, and comprehensively and accurately captures the competencies of HL.	Recommendations regarding the use of the validated scale and confirmation of its validity is of importance to the research and clinical community.
	Sharma et al.	None.	Flesch–Kincaid and Simple Measure of Gobbledygook (SMOG) formulae were used to identify reading difficulty for the 100 highest Google ranked consumer-oriented stroke web pages	None of the web pages identified complied with the current readability guidelines. Mean Flesch–Kincaid grade level was 10.4 (95% confidence interval [CI] 9.97-10.9) and mean SMOG grade 12.1 (95% CI 11.7-12.4).	Accessibility to and use of websites was not mentioned, and the classification of the rankings was performed by Google.
	Anzuman	None.	A literature review was performed and nurses at the CMMC (Central Maine Medical Center) were consulted to identify best practice guidelines for HL in stroke patients.	The author recommends implementing clinical scenarios into the CMMC HL tools in order to individualize patient education using their current booklet, to improve health literacy of CMMC's current education material for stroke patients, and to implement evidence-based individualized patient education in future	This analysis is restricted to a single medical site in the United States of America and is therefore not generalizable, and no statistical analyses was performed or data collected from patients.

EFFECTIVENESS OF CURRENT EDUCATIONAL MATERIAL	Sanders, et al. 2014	100 stroke survivors admitted to an acute stroke unit.	Prospective hospital-based cohort of inpatients, who received verbal stroke information with illustrative handouts. Health literacy level was assessed. Education retention evaluated using questionnaire.	Low to marginal health literacy found in 59% of patients. Poor stroke knowledge retention; 12% could name all 5 stroke warning signs, 43% knew personal risk factors, 85% knew to call 911 for stroke warning signs.	Verified HL measurement tool was used and diagnosis of acute ischemic stroke was confirmed by a neurologist, or CT/MRI.
	Fang, et al. 2009	183 outpatients taking warfarin for primary and secondary stroke prevention.	Administered survey asking participants to describe indication for warfarin and describe stroke. Also measured health literacy in participants.	Only 9.3% reported purpose of warfarin therapy was to prevent stroke, 40% had inaccurate perceptions of stroke. Inadequate health literacy strongly associated with poor understanding of stroke (OR=5.8 (2.1-15.6)).	Authors did not identify an impact on adherence or warfarin control, rather perceptions and understanding of stroke.
	Levy, et al. 2012	57 non-aphasic stroke survivors.	Retrospective chart of cohort who received group education by occupational therapy, nursing and pharmacy to improve health literacy and introduce medication self-administration strategies. Measured pre- and post-education performance on medication self-administration.	Improved medication self-administration after education. Pre-education performance may be predictive of home discharge with home care vs. no home care.	Authors indicate that improvement of performance immediately after the education session could be due to spontaneous stroke recovery.
	Huang et al., 2015	87 participants recruited from the rehabilitation departments of two teaching hospitals in northern Taiwan.	Mandarin version of SHEAL (short-form Health Literacy Scale) and the Public Stroke Knowledge Quiz (PSKQ) were both administered to participants.	The internal consistency reliability, convergent validity, and discriminative validity of the Mandarin version of SHEAL were adequate, however, the internal consistency reliability and ceiling effect of the SHEAL need to be improved.	There is the potential for sampling biased as the participants were recruited through convenience sampling. As well, there was a risk of external validity and a small sample size.

	Huang et al., 2015	311 patient's data and item parameters were retrieved from a Rasch validation study.	Real data simulations were performed to develop a computerized adaptive test of the European Health Literacy Survey Questionnaire. Both efficiency and reliability of this tool were explored.	The adaptive tool demonstrated suitable reliability in all domains (0.72-0.84) with a mean test length of 17 items as opposed to the original 47-item European Health Literacy Survey Questionnaire.	The author's contributions are meaningful as a reliable tool that has less items is beneficial to developing efficient outcome measures.
	Brzycki, 2020	25 healthcare professionals with experience in educating stroke patients.	Qualitative analysis of interviews and literature review was conducted	The most effective techniques that most staff members agreed on were using teach-back methods and allowing the patient or family members to take notes, highlighting important parts in materials or handouts provided	The study sample was quite small (N=25) and consisted of only healthcare providers, and not patients.
MEASUREMENT HEALTH LITERACY AND STROKE LITERACY IN PATIENTS	Schriner, 2011	30 non-aphasic stroke survivors at community-based education program.	Screened patients for low health literacy using NVS tool. Structured interview to discern media preference.	Two-thirds of sample at risk of limited health literacy. No statistically significant preference for media type.	The authors identify that he association between education and HL levels must be examined with caution as education has been determined a poor indicator of HL.
	Sanders, et al. 2014	100 stroke survivors admitted to an acute stroke unit.	Prospective hospital-based cohort of inpatients, who received verbal stroke information with illustrative handouts. HL level was assessed. Education retention evaluated using questionnaire.	Low to marginal health literacy found in 59% of patients. Poor stroke knowledge retention; 12% could name all 5 stroke warning signs, 43% knew personal risk factors, 85% knew to call 911 for stroke warning signs.	Verified HL measurement tool was used and diagnosis of acute ischemic stroke was confirmed by a neurologist, or CT/MRI.

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	Lee, et al. 2009	214 Chinese stroke survivors.	Semi-structured interviews exploring patient understanding of depression.	Only 40% had heard of depression. Older adults used non-specific terms to describe depression, which may not match diagnostic criteria in screening tools.	No validated measurement tool was used or identified to measure HL with.
	Wong, et al. 2013	411 Singaporean Chinese participants from the community.	Administered questionnaire to assess knowledge of stroke risk factors, warning signs, emergency response, and demographics.	One correct risk factor and warning sign was identified by 88% and 78% of participants, but the correct response was only stated by 38%. Higher education and knowing one's cholesterol were each associated with decreased smoking and alcohol consumption.	Study sample was representative of the Singaporean population. Selection bias is possible as demographic variables were not considered. As well, convenience sampling was used for recruitment.
	Andrade, et al. 2018	1624 participants aged 16-25 in mainland Portugal.	Cross-sectional study design was used and face to face interviews were conducted through a structured questionnaire to assess health literacy.	Participants with higher health literacy had higher cardiovascular health related knowledge. The authors propose new effective health education strategies to improve health literacy and cardiovascular health	The authors acknowledge that the tool used to measure HL was not specific to stroke literacy and therefore might not be an effective or sensitive measure of stroke literacy.

	Pitton, et al. 2018	633 respondents in Santa Maria, Brazil.	Community-based cross-sectional study was conducted from December 2015 to October 2016 to assess stroke literacy.	33% knew the meaning of "AVC"; 29.5% incorrectly localized stroke to be in the heart. 50.7% of participants could not recall any symptoms of stroke. Higher levels of education were positively associated with higher stroke literacy levels.	Convenience sampling methods as well as a higher median years of schooling estimate for the study population indicate that results are not generalizable to the Brazilian population.
	Morren & Salgado, 2013	298 participants from the 2006-2010 Cleveland Clinic Florida annual 'stroke prevention screening' questionnaires.	Used cohort data to identify stroke risk awareness proficiency based on questionnaire answers.	74.2% showed stroke risk factor awareness, 28.2% were stroke symptom aware, 17.8% had stroke literacy, 87.9% declared appropriate stroke behavior and 16.1% had stroke proficiency.	The cohort's population was identified as quite affluent, as well minority communities were not included therefore the results are not generalizable.
	Willey, Williams, & Boden-Albala, 2009	1,023 participants, predominantly African Americans, in Central Harlem, New York	Administered in-person closed-ended questionnaires focused on stroke symptoms and risk factors	53.7% of respondents identified stroke occurred in the brain, 20.8% identified stroke occurred in the heart. African Americans (OR 2.20, 95%, CI 1.09-4.45) and Hispanics (OR 5.27, 95% CI 2.46-11.30) were less likely to identify the brain as the damaged organ in stroke.	The authors effectively target a high-risk stroke population. The authors rightfully suggest culturally tailored educational campaigns as an effective mechanism for raising awareness and stroke literacy.
	Clairmont, Fey, & Adcock, 2020	24 patients with ischemic stroke using cross-sectional survey study	Assessment of stroke health literacy in on the inpatient service was determined through questions from a modified version of the Stroke Knowledge Test. Post-stroke depression also assessed	patients with fewer known stroke risk factors may have a poorer understanding of stroke. Interestingly, higher health literacy was associated with higher HAMD scores.	Study population for a quantitative analysis was quite small (N=24) and restricted the power of the calculation, as well as the generalizability.

	Zhao, Zhao, & Li	588 participants in the high-risk stroke population aged 45–69 years in Jilin province, China	HL was assessed through questionnaire distribution and completion. Demographic data regarding family function, marital status, and socio-economic status was also gathered.	The health literacy level of the high-risk stroke population was 18.03%, which indicated that the overall level was low. Household income, marital status, and family function were influencing factors of health literacy.	A subset of the demographic (high-risk participants) were included, therefore the representative sample size was limited. Only general demographic characteristics were gathered.
	Martinez et a., 2016	145 stroke patients, 72 Hispanic identifying and 73 non-Hispanic White identifying recruited from the general community.	Authors performed prospective study of stroke patients from an academic Stroke Center in Arizona and surveyed members of the general community. Questionnaires included: the Duke Social Support Index (DSSI), the Multidimensional Health Locus of Control (MHLC) Scale, a stroke barriers questionnaire, and a Stroke Awareness Test.	Hispanics scored lower on the Stroke Awareness Test compared to NHWs (72.5% vs. 79.1%, $p = 0.029$). Hispanic stroke patients reported greater barriers related to medical knowledge, medication adherence, and healthcare access ($p < 0.05$ for all)	Stroke severity was not included as a variable in the analysis, and the population was likely biased towards less severe strokes as the sampling population included only those able to complete the assessments.
EFFECT OF HEALTH LITERACY ON BEHAVIOURS AND OUTCOMES IN PATIENTS	Wong, et al. 2013	411 Singaporean Chinese participants from the community.	Administered questionnaire to assess knowledge of stroke risk factors, warning signs, emergency response, and demographics.	One correct risk factor and warning sign was identified by 88% and 78% of participants, but the correct response was only stated by 38%. Higher education and knowing ones cholesterol were each associated with decreased smoking and alcohol consumption.	Study sample was representative of the Singaporean population. Selection bias is possible as demographic variables were not considered. As well, convenience sampling was used for recruitment.
	Diug, et al. 2011	157 cases and 329 controls from the community.	Case-control study in community. Cases were patients stabilized on warfarin with previous INR >6.0. Controls were patients with therapeutic INR. Structured interview to assess predisposing factors.	Impaired cognition (OR=1.9 (1.0-3.6)) and inadequate health literacy (OR=4.0 (2.1-7.4)) were associated with elevated INR.	Recruitment methodology is robust and the sample size is inflated for potential confounding variables.

	Biermann, et al. 2011	2487 adults.	Cohort study, underwent clinic assessment and completed questionnaires assessing physician diagnosed conditions. Also measured health literacy.	Inadequate health literacy associated with stroke (OR=1.88 (1.08-3.26)), diabetes (OR=1.76 (1.20-2.57)) and hypertension (OR=1.78 (1.29-2.46)).	Strengths include using physician diagnoses to identify outcomes and a longitudinal study design. Demographic characteristics not controlled for in analysis.
	Bhatnagar, et al. 2002	97 Indian aphasic stroke survivors.	Examined association between age, gender and education-level with aphasia type.	Mean age of aphasic patients was significantly lower than in Western countries. Non-statistically significant trend of more devastating strokes at younger age in patients with less education.	Confusion of birthdate was common with patients who reported to be not educated.
	Arif, et al. 2007	298 stroke and 275 MI survivors.	Retrospective cross-sectional telephone survey of patients' post-discharge, and chart-review to assess medication compliance.	Only 68% of stroke patients were adherent with at least half of their discharge medications compared to 90% of MI patients. Education (non-medical) was associated with improved compliance.	Social norms or self-perception of disease are potential effect modifiers. The stroke and MI groups had significantly different baseline characteristics.
	Nazar et al. 2019	100 university students in Pakistan	Pre and post cross sectional study design was used to assess lifestyle and behavioral changes.	By attending educational sessions thought to increase health literacy, significant positive changes in behavior and knowledge was observed. The authors conclude that education and health promotion can be effective ways of increasing health literacy and simultaneously decreasing cardiovascular disease risks.	Excluded medical students from the study population to ensure generalization. Time and funding constraints were the authors' identified limitations.

	Tian, et al. 2018	20 male and 10 female patients admitted to a hospital.	The validated s-TOFHLA tool used to assess health literacy was given to patients and associated with their length of stay at the hospital.	67% were determined to have adequate health literacy and 33% had inadequate health literacy. Those with adequate health literacy had an average length of hospital stay of 1.33 days, where those with inadequate health literacy had an average stay of 5 days.	Study population for a quantitative analysis was quite small (N=30) and restricted the power of the calculation. Analytical model was not adjusted for demographic factors.
	Rolls, et al. 2017	48 patients with history of atrial fibrillation identified by general practices	Cross-sectional survey, using The Anticoagulation Knowledge Tool (AKT) to assess knowledge.	Lower HL levels indicated less knowledge and understanding of medication prescription (57.1% vs 85.2%, P = .04), how the medication works (42.9% vs 88.9%, p = .001), and the associated side effects (28.6% vs 70.4%, p = .03).	Quality of education was not assessed at baseline. Medication history and other comorbidities that could influence the outcome were not considered.
	Appleton, et al. 2015	2487 South Australian adults' part of the North West Adelaide Health Study.	Administered clinical and biomedical assessments as well as self-reported diagnoses of stroke related outcomes, and functional health literacy was measured through the Newest Vital Sign measure.	Functional health literacy was significantly associated with stroke related risk factors such as depression, hypertension, and smoking.	The North West Adelaide Health Study provides a representative biomedical cohort for this analysis. The authors however found an association between health literacy and stroke related outcomes, not with stroke itself.
	Sanders, et a. 2014	Patients older than 18 admitted to the hospital stroke unit with a diagnosis of acute ischemic stroke who were able to provide informed consent to participate (N = 100)	Health literacy levels were measured by using the short form of Test of Functional Health Literacy in Adults. They assessed education outcomes for poststroke care education, knowledge, and retention.	Of the 100 participants, 59% had inadequate to marginal health literacy. Stroke patients who had marginal health literacy or adequate health literacy had higher education outcome scores than those identified as having inadequate health literacy.	There exists a lack of evidence or predictive validity surrounding stroke patient education outcomes, such as retention in care and patient adherence.

Theme 1: *Patient Preferences Regarding the Formatting and Content of Educational Materials, and Perceived Barriers*
Eight articles studied patient preferences and opinions regarding stroke-related material, which were further subdivided into preferences regarding the information medium, layout, content, and barriers to access.

a) Information Medium

Four studies examined patient preferences for modality of information presentation [21-24]. One article found that patients in-hospital preferred a combination of written and verbal information [21]. The second article evaluated patient preferences for written, video and computer-based information prior to and after exposure to all three modalities [22]. Consisting of a sample of 30 non-aphasic stroke survivors, there was a statistically non-significant shift in preferences from written to video and computer-based material after exposure to all three modalities. The author suggests that this trend may be a result of patients selecting material based on familiarity at first, but then preferring material with visual input and images [22]. The third study focused specifically on video narrative focused educational materials, claimed culturally appropriate for the local context [23]. The authors reported the video tools were useful and inspiring to the 8 participants involved in in-depth telephone interviews [23]. The fourth study implemented augmented reality (AR) mechanisms for stroke education [24]. The authors identified that the AR group scored significantly higher in the perception that they had become better able to explain stroke to other people ($P<0.01$); that they found it easier to understand the anatomy ($P<0.01$); found it more useful compared to the pamphlet group ($P<0.05$); and enjoyed using the resource more than the pamphlet group ($P<0.001$) (24).

b) Layout and Formatting

Four studies assessed patients' layout preferences [25-28]. Two articles found that stroke survivors generally requested more diagrams, and felt that simplifying language, avoiding medical jargon, using large font size, and organizing information simply and logically would improve comprehension

Two of the studies exclusively examined aphasic patients [26,27]. The majority (62.4%)—especially patients with greater aphasia severity or more recent stroke—preferred numbers to be expressed numerically rather than as words. In terms of disease-related written information formatting, fourteen-point font was most commonly preferred (28.2% of patients), while 33.3% favoured Verdana typography. Participants also preferred colour and diagrams to support text [20,22], with 95% considering graphics to be helpful, and the preferred graphic format was photographs [27]. These findings were somewhat congruent with recommendations from guidelines.

c) Content

We identified five studies examining patient satisfaction and preferences regarding content of educational materials [25,29,30]. The majority of patients felt their information needs were not completely met in-hospital. Although patients were satisfied with information regarding lifestyle and health promotion, incontinence, and current treatment, there was poor satisfaction with general stroke information, including: impairments, treatments, community services, legal and financial affairs, and how to access information.

Two papers highlighted the need to individualize teaching material as information demands vary considerably with patients requesting information on a mean of 10 topics [25,30]. These demands evolved over time, with patients initially seeking information regarding the causes and prognosis of stroke, but prevention of future strokes upon discharge [25,26].

Additionally, patients were less satisfied with materials written at higher grade levels or had lower suitability scores as assessed by the Rate Index (RIX) and Suitability of Assessments (SAM) tools. Donnellan, et al. found that patients felt that improved understandability of content may better facilitate their self-efficacy in positively modifying health behaviours, mitigating lifestyle disturbances secondary to new medication and their adverse effects, and managing increased fatigue [29].

d) Barriers

Eames, et al. conducted qualitative interviews with patients and identified three major barriers to stroke education: limited availability and suitability of information; the hospital environment; and patient and carer factors [26].

Martinez et al. identified that Hispanic stroke patients reported greater barriers related to medical knowledge, medication adherence, and healthcare access ($p < 0.05$ for all) when compared to non-Hispanic Whites [31].

Patients felt they received an inadequate amount of information and did not know where to access it [26,30]. Hoffman & McKenna emphasized the difficulty in accessing material, with only a minority of patients (22.8%) reporting receiving information in hospital. Another study identified that 75% of stroke survivors felt their informational needs were only partially met in hospital, with nearly half not recalling receiving written information at all [25]. Patients also felt that not receiving relevant information, having information presented at inappropriate times, and receiving material with poor layout or wording were also barriers [25-27].

Patients also identified barriers including poor continuity of care resulting in disruption of normal service delivery, and hospital staff having limited opportunity to answer questions [26]. Finally, patient barriers included having insufficient time to gather information; and patients not asking for information for a variety of reasons, including feeling uncomfortable approaching staff, not knowing what to ask, being in denial, or feeling overwhelmed [26].

Theme 2: *Assessment of the Appropriateness of Current Educational Materials*
We identified six studies evaluating the appropriateness of current stroke educational materials in regard to readability and layout; including 2 studies only available as abstracts as they were presented at conferences [25,30,32-35]. Articles assessed the readability of material using either the RIX or Simplified

Measure of Gobbledygook (SMOG) [30,35]. Guidelines recommend educational materials to be written at or below a sixth grade reading level [36].

Three articles examined written material provided by hospital staff and national stroke agencies. These materials were generally found to be written at a high school reading level, with a mean RIX grade 9 reading level, or a mean SMOG grade 11 reading level. One article attempted to attain the suggested sixth grade reading level through aggressive editing (severely modifying the original content to match desired reading level) of materials but failed to do so [25,30,35].

Fitzsimmons et al. completed an internet Google search to identify the 100 highest ranked webpages containing patient oriented stroke information and found that only 6% of webpages were written at or below the recommended 6th grade reading level. Articles were found to be written at an overall mean FKGL grade 10.2 level [32]. Commercial websites were easier to read than non-commercial websites, with a mean FKGL grade 8.63 (7.92-9.34) compared to 11.0 (10.1-11.8) level. Similarly, Sharma et al. completed a readability assessment of the 100 highest ranked webpages containing available online stroke material. Reading difficulty was assessed using the Flesch–Kincaid and Simple Measure of Gobbledygook (SMOG) formulae. The authors identified that none of the included web pages complied with the current readability guidelines as suggested by the gold standard SMOG formula [34].

Two studies assessed the reading ability of stroke patients through the Rapid Estimate of Adult Literacy in Medicine (REALM) tool. Both articles found patients without aphasia read at a mean 7-8th grade reading level, while aphasic patients read at a mean 4-6th grade reading level [25,30].

Educational materials were formally assessed with the SAM tool, which evaluates content, literacy demands, graphics, layout and typography, learning stimulation and motivation, and cultural appropriateness. Hoffman and McKenna determined that written materials were most often inadequate in terms of content (44.4%), literacy demand (77.8%), or containing a summary (94.4%); adequate in typography (66.7%); and superior in overall layout (72.2%) and cultural appropriateness (100%) (30). Both studies found the majority of the material ranged from inadequate to adequate in overall appropriateness [25-30].

Huang et al. formally assessed the appropriateness and validity of the European Health Literacy Survey Questionnaire (HLS-EU-Q)[33]. Model deviance, unidimensionality of each domain, local independence, item fit, response categories, and differential item functioning (DIF) were assessed, and the authors identified that the original 47-item HLS-WU-Q was effective when Rasch analysis was performed.

The final study was a capstone for Dr. Anzuman. With a literature review and consultations with registered nurses at Central Maine Medical Center (CMMC), the author recommends implementing clinical scenarios into the CMMC HL booklet to individualize current education material used by CMMC for stroke patient, to improve health literacy of CMMC's current education material for stroke patients, and to implement evidence-based individualized patient education in future [37].

Theme 3: Assessment of the Effectiveness of Current Educational Materials

Our search identified seven studies evaluating the effectiveness of educational materials, two of which were presented at conferences and were only available as abstracts, one of which was a doctoral dissertation [21,38-42]. Two studies assessed patients' understanding of stroke and stroke therapy [39.43]. One study found that only 12% of patients were able to name the five emphasized warning signs of stroke, 43% recognized their own personal risk factors, 85% knew to call 911 when observing stroke warning signs, 76% knew their stroke medications, and 53% of patients knew their stroke type after standard education. Similarly, a different study found that only 33% of patients stabilized on warfarin for stroke prevention were able to describe a sign or symptom of a cerebrovascular accident (CVA); 43% did not understand their indication for therapy, and only 9.3% specifically identified warfarin for stroke prevention.

A third study assessed whether education improved self-administration of medication in non-aphasic stroke survivors by measuring performance on the Hopkins Medication Schedule (HMS), an objective test of a patient's ability to understand and implement a routine prescription medication [21,44]. The researchers noted that education improved mean HMS scores from 4.8 to 6.0 [21]. Additionally, a cross sectional study gathering retrospective data in stroke patients found lower pre-education HMS scores were associated with home discharge with care services versus discharge without help, but not with home versus nursing facility disposition; investigators found no association between MMSE scores and needing skilled help [45]..

A fourth paper looked at the internal consistency, reliability, convergent validity, and discriminative validity of the Mandarin version of SHEAL (short-form Health Literacy Scale) when the Public Stroke Knowledge Quiz (PSKQ) was used to identify convergent validity[40]. They found that the scale was indeed adequate, (alpha = 0.82) and high correlation with the PSKQ (r = 0.62) but, the internal consistency, reliability, and ceiling effect of the SHEAL needs improvement (40). The same authors in 2020 modified the European Health Literacy Survey Questionnaire to a condensed and computerized adaptive test [41]. The authors found that their version provided suitable reliability in all 12 domains of HL assessed (0.72–0.84).

The fifth paper examined the efficacy of using the Teach Back and Ask Me 3 methods in the stroke population [38]. Teach Back is a commonly used patient education tool, which allows the healthcare provider to assess patient understanding by asking the patient to paraphrase information taught to them [46]. Ask Me 3 is another education tool used to empower patients by having them ask healthcare workers three questions at each visit [47]. The use of these tools was shown to result in a 17% improvement in patients' understanding of their diagnosis, their treatment plan, and the importance of their treatment plan [38]. The sixth paper and doctoral dissertation focused on the available methods of post-stroke education and care [42]. Dr. Brzycki also identified that most effective techniques that most staff mem-

bers agreed on were using teach-back methods and allowing the patient or family members to take notes, highlighting important parts in materials or handouts provided [42].

Theme 4: Measurement of Health and Stroke Literacy in Patients

We identified ten articles measuring HL relevant to stroke [39,43,48-54].

Nine studies observed low levels of HL among participants. Sanders, et al. measured HL in hospitalized patients with acute ischemic stroke and found that 59% of survivors had low-to-marginal abilities based on the short-form Test of Functional Health Literacy in Adults (S-TOFHLA) [43]. Similarly, Schriner, et al. examined HL levels in non-aphasic stroke survivors using the Newest Vital Sign (NVS) tool and found 23% of survivors had marginal or inadequate literacy, while an additional 50% were at risk of limited literacy [52]. Clairmont, Frey, and Adcock found that participants with 3 or more stroke risk factors scored significantly higher on the health literacy exam (M= 63.6) compared to those with 2 or less stroke risk factors (M= 50, $p<0.001$)[48]. Pitton, et al. showed that 29.5% of their Brazilian study population incorrectly localized stroke to be in the heart, and 50.7% of participants could not recall any symptoms of stroke [51]. Morren & Salgado used a stroke prevention screening questionnaire administered as a part of a cohort study in Florida, United States, and identified that although 88% of patients were stroke literate, only 18% were aware of stroke symptoms and 28% were aware of risk factors [50]. Willey, Williams, & Boden-Albala studied a subpopulation of predominantly African Americans and Hispanic peoples in Harlem, New York and found that just over half (53%) could identify that stroke occurred in the brain and that African Americans (versus White) were significantly less likely to identify the brain as the damaged organ after a stroke episode [53]. Similarly, Martinez et al. surveyed 145 stroke patients, 72 of which identified as Hispanic and 73 participants identified as non-Hispanic Whites (NHW) [31]. This study found that Hispanics scored lower on the Stroke Awareness Test compared to NHWs (72.5% vs. 79.1%, $p = 0.029$).

Two papers used the S-TOFHLA to examine patients who had received at least 3 months of warfarin therapy for stroke prevention [39,49]. Fang, et al. found inadequate levels of HL in 52% of patients, marginal levels in 12% of patients, and adequate levels in only 36% of patients taking warfarin. Inadequate HL measured using the tool was associated with a poorer understanding of stroke. Not speaking English, and having less than a college education were independently associated with misunderstanding the purpose of warfarin for the outpatients taking warfarin. Diug, et al. found patients with elevated levels of a marker of warfarin stability, International Normalized Ratio (INR), to be more likely to have inadequate or marginal HL compared to controls with therapeutic INRs.

Three studies examined HL in Asian cultures. One trial specifically assessed depression literacy among stroke patients in Hong Kong, as this condition is common amongst CVA survivors. Lee, et al. found that 60% had never heard of depression, with only 33% wanting to learn more. The second study assessed stroke knowledge amongst the general public in Singapore through questionnaires and found that while most were able to list at least one risk factor (88%) or warning sign (78%), only 38% were able to list the correct emergency response to a stroke. In the third study, Zhao, Zhao,& Li identified that the HL levels in high-risk stroke patients in Jilin Province, China was only 18.03%, indicating severely low levels of HL overall in this population. They also identified that various demographic variables, specifically income, marital status, and family function, influenced HL levels in this population [55-56].

Theme 5: The Effect of Health Literacy on Behaviours and Outcomes in Patients

We identified ten studies assessing the effect of HL on behaviours and outcomes in stroke patients and the general population. One paper was presented at conference and only available as an abstract [15,25,43,45,49,55,57-,60].

a) Health Behaviour/Outcomes

In a random sample of Chine Singaporean's, higher education was associated with less smoking and drinking. Conversely, not knowing one's cholesterol at the time of questionnaire administration was associated with increased smoking and drinking, which are known risk factors of stroke [55]. However, the majority of the participants were able to identify a risk factor (88%) and a warning sign (78%) of stroke [40].

Biermann, et al. assessed HL among 2400 Australians with the NVS tool, and found that inadequate HL was independently associated with stroke, diabetes, and hypertension but not smoking. Bhatnagar, et al. studied 97 stroke survivors in India, and found a trend of more devastating stroke at younger ages in patients with less formal education; however, statistical analysis was not conducted. Similarly, Appleton, et al. found functional HL to be associated with stroke related factors such as hypertension, smoking, and diabetes in Adelaide, Australia [60].

Rolls, et al. found that participants with inadequate HL were less likely to know why they had been prescribed an oral anticoagulant, how it worked, or describe a side effect in population of patients taking oral anticoagulants for stroke thromboprophylaxis [15].

Tian et al. found that 33% of stroke patients admitted to hospital (30 patients total) had inadequate levels of HL as identified using the validated s-TOFHLA tool, and that length of hospital stay was inversely related to HL levels. Patients with inadequate HL stayed an average of 5 days compared to 1.33 days for those with adequate HL [58].

Sanders et al. broke down HL into three categories: adequate, marginal, and inadequate. They determined a strong relationship between HL levels—identified through the use of the short form of Test of Functional Health Literacy in Adults—and stroke education outcomes, specifically between those with what they defined as adequate HL versus those with inadequate HL. Marginal HL levels, however, were not significantly associated with different stroke education outcomes [43].

b) Stroke Management and Medication Adherence

Three studies examined the effect of literacy on stroke management [45,49,59]. One paper compared medication compliance between post-stroke and post-myocardial infarction (MI) patients in Pakistan and found only 68% of stroke patients to be adherent with at least half of their discharge medications compared to 90% of MI patients [45]. Any level of general education was associated with improved compliance in stroke patients [45]. The second study was conducted in Australia and found that inadequate HL in patients stabilized on warfarin was associated with an increased risk for INR ≥6.0 [49]. The third study examined 100 university students in Pakistan attending educational sessions thought to increase HL. Using a pre and post cross-sectional study design identified lifestyle and behaviour changes observed clinically significant positive changes in behaviour and knowledge. [59].

Discussion

Stroke presents significant challenges and important opportunities for HL—including the tendency of patients (and in many cases health care professionals) to use "an acute paradigm" that anticipates rapid onset, overt symptoms, and a timely resolution. With stroke, however, there is a need to accept chronicity, cognitive decline, and understanding complex concepts such as multifactorial risks and the interplay of co-morbidities.

This review identified a multitude of limitations with the current educational tools, as we intended to explore in our first objective. Many studies found that the educational materials layout and formatting could be improved, and that more interactive and video information mediums were preferred. Studies also identified barriers to access, understand, and utilize the educational materials already available. This shows that there are not only limitations with the current tools used to identify HL and similar domains for stroke patients, but also significant barriers to accessing these materials, understanding, and utilizing them to improve the health status of stroke patients and their respective health outcomes. Furthermore, there is evidence that stroke patients prefer and benefit from information written and formatted clearly and concisely; however, these conclusions are limited by a lack of studies offering a comprehensive assessment that includes each of these factors, consequently requiring one to extrapolate results and create inferences across heterogeneous papers and populations. These limitations may be compounded by flaws inherent to the tools used to measure the quality of resources and levels of HL [21,25,38,44,61,62,].

Successful stroke management relies upon the HL of patients, which influences their ability to process and act on health information [61]. Additionally, this process is often contingent on clinicians having the skills and quality resources to provide information effectively [63]. HL impacts an individual's learning abilities and needs, and influences patient-perception of quality of resources. Evidence suggests improved HL is correlated with improved self-management, which is beneficial for both the individual and the health system [12,13]. In addition to improving an individual's capacity to utilize information and services effectively, improved HL empowers the population to control a number of modifiable determinants of health. Ultimately, this improves quality of care and efficient use of resources.

Current HL measurement instruments have several well recognized weaknesses [12]. With no established gold standard, there is significant variability in the design, purpose, and implementation of these tools. While certain instruments have been developed as quick clinical screens, such as the REALM (64,65), TOHFLA, and NVS, while others, such as the Health Literacy Management Scale (HeLMS) are more in-depth [66=69]. Other weaknesses of instruments include focusing largely on personal, rather than population-based characteristics and not accounting for care provider and health professional related factors [39]. Furthermore, existing measurement tools fail to identify specific areas of weakness or strategies to improve HL—including skill improvement and empowerment. Finally, these instruments have limited test validity and reliability, and offer only weak associations with outcomes [70]. As such, these tools are heterogeneous instruments with questionable applicability and generalizability. In light of our second objective, we ultimately found that the studies that utilized these tools and others to identify HL in stroke populations found that generally, the levels of HL in stroke patients were indeed not sufficiently high, and in many cases quite low [39,43,49,51,53].

We found several papers centered around our third objective focused on the impacts of measured levels of HL and stroke literacy within stroke patient populations on health-related behaviours and outcomes. Several articles highlighted poor levels of HL in stroke patients, and there is a general consensus of low HL levels within minority communities and immigrants [22,25,57,66,68,71]. Low levels of HL have been associated with poor patient outcomes in stroke patients in several of the studies found. These health outcomes include general health status, self-reported health, and medication adherence [15,72].

Aside what we have summarized, we have identified a paucity of literature—despite our robust and comprehensive search strategy—analyzing the cumulative effects of HL on patient outcomes, and even fewer offering a summative assessment of the relationship between stroke education resources, HL, and outcomes. Current tools and HL measures assessing readability and appropriateness of health-related information provide limited information with questionable significance. These findings beget the questions – *how do we effectively assess the HL of stroke patients? How do we adequately determine the appropriateness of the available educational materials for these patients? And how do the health outcomes of stroke patients improve as their HL/stroke literacy improve?* This review highlights the importance of HL in health care practice and health policy, the need to develop additional tools to assess HL, and develop best-practice guidelines for stroke education materials.

Limitations

This study included both journal publications, and gray literature sources to ensure that the review is a fulsome capture of the literature that exists around stroke and HL. The authors recognize that the review may be limited as the methodological quality of articles considered might not be adequately assessed. Additionally, exclusion of all non-English papers may have caused us to miss relevant articles published in different languages.

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