DETERMINING THE LEVEL OF HEALTH LITERACY AND EXPLORING ASSOCIATED CONTEXTUAL FACTORS IN RECENT MINOR ISCHEMIC STROKE SURVIVORS RETURNING TO THE COMMUNITY

DETERMINING THE LEVEL OF HEALTH LITERACY AND EXPLORING ASSOCIATED CONTEXTUAL FACTORS IN RECENT MINOR ISCHEMIC STROKE SURVIVORS RETURNING TO THE COMMUNITY

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TITLE: Determining the Level of Health Literacy and Exploring Associated Contextual Factors in Recent Minor Ischemic Stroke Survivors Returning to the Community

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Abstract

Background: In Canada, as acute ischemic stroke treatment advances and the population ages, more individuals are surviving stroke and returning home with minor deficits. Self-management education tailored to one's health literacy level is a critical and overlooked aspect in minor ischemic stroke survivors' recovery. During the first month after minor ischemic stroke, when the risk of recurrence is highest, minor ischemic stroke survivors experience numerous transitions and report unmet health information needs that place them at risk for poor health outcomes. Although minor ischemic stroke-specific data is lacking, American data suggests 59% of stroke survivors have marginal to inadequate health literacy at the time of hospital discharge. Low health literacy in stroke survivors has been associated with poor education retention; issues with medication administration, adherence and self-efficacy; reduced physical functioning; and depression. Increasingly it is recognized that health literacy should be considered a contextual entity. There is a need to better understand the level of health literacy and contextual factors associated with health literacy in minor ischemic stroke survivors to prevent poor health outcomes and health disparities.

Purpose: This project aimed to determine the level of health literacy and contextual factors associated with health literacy in recent minor ischemic stroke survivors who were predicted to return to the community within 30 days after their stroke.

Methods: This cross-sectional survey was grounded by Sorensen's Integrated Model of Health Literacy (2012) and employed the HLS19-Q12 to measure health literacy. Contextual factors were assessed using a survey developed from a comprehensive literature review. Forty-two minor ischemic stroke survivors were recruited from the acute stroke unit and stroke rehabilitation unit and completed the questionnaires. Statistical analyses were completed in

SPSS. Summary statistics of the HLS19-Q12 scores in minor ischemic stroke survivors were reported and compared with HLS19-Q12 scores of the general population published in the2019-2021 Health Literacy Population Survey. Contextual factors were reported as summary statistics and associations with health literacy were analyzed using Spearman correlation, Kruskal-Wallis tests, Mann-Whitney U tests and multiple linear regression.

Results: The average HLS19-Q12 score was 76.3 and similar to the results obtained in the 2019-2021 Health Literacy Populations Survey. The need for information about financial support, a higher number of total barriers to health literacy and issues related to health care provider continuity, feeling uncomfortable asking a health care provider to explain something you didn't understand (stigma) and memory were associated with lower levels of health literacy in recent minor ischemic stroke survivors.

Discussion: Although the average level of health literacy was similar to that of the general population, many participants reported problematic (26.2%) or inadequate (16.7%) health literacy. This thesis is unique in its use of a contextual perspective to explore health literacy in minor ischemic stroke survivors. This perspective enabled the identification of personal, situational and societal/environmental factors that may be critical in promoting optimal health of recent minor ischemic stroke survivors. The results of this study suggest care continuity, the patient-health care provider relationship and financial support may be critical factors.

Conclusion: This data can be used to inform future equity-focused research designs and holistic interventions to support recent minor ischemic stroke survivors with lower levels of health literacy who return to the community. These interventions have the potential to reduce the risk for poor health outcomes after a minor ischemic stroke.

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List of Abbreviations

ASU	Acute Stroke Unit
CFS	Contextual Factors Survey
CI	Confidence Interval
CNS	Clinical Nurse Specialist
CT	Computed Tomography
HCP	Health Care Provider
HiREB	Hamilton integrated Research Ethics Board
HLS	Health Literacy Survey
HLS19S	Health Literacy Population Survey Project 2019-2021
IMoHL	Integrated Model of Health Literacy
iRU	Inpatient Rehabilitation Unit
MIS	Minor Ischemic Stroke
MRI	Magnetic Resonance Imaging
NIHSS	National Institute of Health Stroke Scale
NP	Nurse Practitioner
PCP	Primary Care Provider
REALM	Rapid Estimate of Adult Literacy in Medicine
SPC	Stroke Prevention Clinic
s-TOFHLA	Short Test of Functional Health Literacy in Adults
TIA	Transient Ischemic Attack

Declaration of Academic Achievement

This thesis reports the original research that I have conducted under the supervision of Drs. Patricia Strachan, Diana Sherifali and Noori Akhtar-Danesh since September 2020. The supervisory committee members provided their expertise towards the research proposal and protocol, Hamilton Integrated Research Ethics Board submissions, study conduct, data management and all chapters of the thesis dissertation. Statistical analyses were completed by myself with expert consultation and verification of results from Dr. Noori Akhtar-Danesh.

Table of Contents

List of Appendices

List of Tables

Determining the Level of Health Literacy and Exploring Associated Contextual Factors in Recent Minor Ischemic Stroke Survivors Returning to the Community

This thesis consists of six chapters: introduction; literature review; methods; results; discussion, implications, strengths and limitations; and conclusion. The introduction provides a high-level overview of the issue, population of interest and focus of the thesis. The second chapter describes the structured literature reviews that were completed throughout the thesis and the key findings of those reviews. The methods and results chapters describe a study that was conducted to address the research questions and objectives of this thesis. The discussion provides an interpretation of the results of the study considering the existing literature. Practice, research, education and policy implications are then presented, followed by a consideration of the strengths and limitations of the study. Finally, the conclusion chapter summarizes the key findings.

Chapter One: Introduction

Overview of Stroke:

In Canada, a stroke occurs every ten minutes and the number of individuals over 20 years of age who go on to live with stroke and its sequalae is equivalent to the population of New Brunswick (741,800) (Heart and Stroke Foundation, 2017). As the Canadian population ages, it is estimated that the overall occurrence of stroke will increase by one percent annually (Public Health Agency of Canada, 2017). Stroke is the tenth largest contributor to disability-adjusted life years (Kassebaum, 2016) and costs Canadians approximately 2.8 billion per year (Mittman, 2012). After age 55, the prevalence of stroke rises sharply and 75% of strokes occur in individuals over 65.

Stroke presents as a sudden loss of brain function caused by an interruption of blood flow to the brain from either a blocked artery (Ischemic Stroke, 85%) or bleed (Hemorrhagic Stroke, 15%) causing permanent brain damage (Musuka et al., 2015) that persists beyond 24 hours or is visible on Computed Tomography (CT) or Magnetic resonance imaging (MRI) (Sacco et al., 2013). A Transient Ischemic Attack (TIA) is most often defined as "a transient episode of neurological dysfunction caused by focal brain, spinal cord, or retinal ischemia, without acute infarction" (Easton et al., 2009, p 2281). More recently this tissue-based definition of TIA has been challenged as specialized diagnostics have identified that infarction is likely to occur in most cases. However currently available standard diagnostic tools are often unable to detect it (Easton & Johnston, 2022; Nadarajan et al., 2014). A formal change in the definition has yet to be widely adopted. As TIAs are undetectable on standard neuroimaging, there is an increased risk of classifying a TIA "mimic" as a TIA (Nadarajan et al., 2014). Regardless of the definition, it is agreed that true (non-mimic) minor ischemic stroke (MIS) or TIA carries a high risk for recurrence and immediate preventative measures are required to reduce the risk of future stroke (Easton & Johnson, 2022; Easton et al., 2009; Johnston, 2002).

In Canada, one-third of stroke survivors return to the community directly from the ED with a referral for outpatient stroke services. Among patients admitted to the hospital with acute stroke, 59% are discharged home without inpatient rehabilitation and 16% receive inpatient rehabilitation (Mountain et al., 2020). Among those discharged home without inpatient rehabilitation, 71% are considered independent at discharge and do not receive formal home care (Mountain et al., 2020). The most common tool for assessing stroke severity is the National Institute of Health Stroke Scale (NIHSS), which categorizes stroke within a range from no detectable symptoms to severe. The NIHSS correlates well with brain infarct size, clinical severity and long-term outcomes (Brott et al., 1989; Yaghi et al., 2016). A critique of the NIHSS, however, is that it does not capture more subtle cognitive or executive function impairments or distal hand weakness (Yaghi et al., 2016) and it is less sensitive to deficits caused by posterior circulation strokes (Libman et al., 2001).

Importance of Patient Education for Stroke Survivors

In Canada, 88% of individuals over 65 have inadequate health literacy (Public Health Association of British Columbia, 2012). Given that 75% of stroke survivors are over age 65 (Heart and Stroke Foundation, 2017), we can extrapolate that a significant number of stroke survivors have pre-existing low health literacy. In older adults, low health literacy is associated with known stroke risk factors (Wolf, Gazmararian & Baker, 2007; Lindahl et al, 2020), low medication adherence (Rolls et al., 2017), 30-day re-hospitalization (Mitchell, Sadikova, Jack, & Paasche-Orlow, 2012), and low adoption of recommended health screening and high healthcare costs (Macleod et al., 2017). Low health literacy in stroke survivors has been associated with hospital readmission (Bushnell et al., 2013). The American Heart Association (2018) suggests that limited health literacy is a major barrier to achieving good cardiovascular health as individuals with limited health literacy are less likely to recognize elevated blood pressure, relapse on smoking cessation, be overweight and experience complications of diabetes which are all known risk factors and targets of secondary stroke prevention education (Magnani et al., 2018). These findings suggest a clear association between low health literacy and poor health outcomes.

As a research nurse working in stroke, I heard from stroke survivors and witnessed their difficulty interacting with health information early in the stroke recovery journey (e.g., understanding the cause of the stroke or the results of numerous investigations, challenges completing medical forms, applying risk reduction strategies, or determining whether the symptoms they are experiencing were due to the stroke or something else. This experience shaped my perception that during this critical period, the information needs of some stroke survivors remain unmet by their current health literacy skills and health system structures.

This perception is consistent with findings from Crow (2018), who found that information about stroke prevention is the highest self-reported unmet need two weeks after discharge home from an ASU. Stroke survivors and their carers report not knowing what to ask, staff being too busy and carers having limited time to find information as barriers to accessing and understanding health information after stroke (Eames et al., 2010). In a qualitative study of community-dwelling first-time stroke survivors participating in stroke rehabilitation, many stroke survivors demonstrated low health literacy and felt that their needs to learn about their stroke were often ignored in busy clinical settings prior to hospital discharge (Chen et al., 2016). Furthermore, qualitative research of stroke survivors within 3-6 months of returning home found that a critical area for quality improvement in clinical practice is enhancing interventions aimed at improving health literacy (Donnellan et al., 2013). These findings suggest that stroke education may not be prioritized in busy ASUs and clinics. Current services are not meeting patients health literacy and education needs. In practice, education delivery may be more strongly influenced by system barriers rather than tailored to the health information needs and health literacy of the stroke survivor. The Canadian Stroke Best Practices recommend that education interventions address varying levels of health literacy; however, valid methods to assess health literacy or ways to target education based on health literacy is not described (Mountain et al., 2020).

As part of this thesis, a literature review was conducted to better understand the landscape of health literacy research in stroke survivors. This literature review is described in chapter two. Although many studies focus on educational interventions in stroke, studies that purposefully explore health literacy after stroke are limited and few have investigated the role of health literacy in an educational intervention's effectiveness or have designed the intervention specific to those with lower levels of health literacy (Aran et al., 2022). Thus, educational interventions studied in participants with adequate health literacy may not reflect the experiences of individuals with low health literacy. For example, Messina et al. (2020) found that an intervention to improve self-management in recent stroke survivors was effective in individuals with higher levels of education but ineffective in those with lower levels of education. Additional research is needed to understand contextual barriers and facilitators associated with achieving adequate health literacy in stroke survivors. This knowledge may support enhanced education interventions and system supports to promote health literacy and self-efficacy in the stroke population.

Conceptualizing Health Literacy

Although definitions of health literacy vary throughout the literature, it is recognized that a limitation of traditional health literacy research is the focus on personal health literacy skills (e.g., reading, writing, oral expression and math) without consideration of the context and how those skills interact with environmental demands and resources to shape the overall health literacy experience (Nutbeam et al., 2018).

The term health literacy originated during a 1974 health education conference in New York when Scott K. Simonds described health literacy as an outcome of health education shaped by both individual skills and the environment and recommended establishing health instruction in primary school (Okan, 2019). The first formal definition of health literacy in school education emerged in 1995, when The Joint Committee on National Health Education Standards defined health literacy as the knowledge and skills "to obtain, interpret, and understand basic health information and services and the competence to use such information and services in ways which enhance health" (p 5).

Unlike school education, the field of adult education and medicine was slow to define health literacy as a unique concept (Okan, 2019). During the 1990s, the association between illiteracy and poor health outcomes was becoming widely recognized through the results of population-based surveys such as the 1994 International Adult Literacy Survey (IALS). This association strongly influenced the conceptualization of health literacy in the adult education and medical fields, by emphasizing the role of functional literacy (e.g., reading, writing, oral expression and math skills) in understanding health information (Okan, 2019). The proliferation of health literacy research in the 1990s produced one of the most widely referenced definitions of health literacy: "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (Ratzan & Parker, 2000, p 4).

Around this time, healthcare was becoming increasingly complex and patients were encouraged to assume a more autonomous and active role in their health (Okan, 2019). Clinician-researchers began investigating the role of health literacy in patient-provider communication, compliance with therapy and self-management. This research shifted the conceptualization of health literacy beyond functional health literacy skills to consider the multidimensional interaction between personal skills, system demands and patient-provider interactions in shaping how patients engage with health information (Okan, 2019). This conceptualization shares health literacy responsibility between patients, providers, organizations and policymakers and recognizes the highly contextual nature of health literacy. Furthermore, it is suggested that to understand the relationship between health literacy and self-management a broader view of health literacy beyond functional health literacy and involving both cognitive and behavioural aspects is required (van der Gaag et al., 2022)

In 2012, Sorensen et al. conducted a systematic review of health literacy definitions and conceptual frameworks as part of the European Health Literacy Project (Sorensen et al., 2012). Through this systematic review, the authors proposed the Integrated Model of Health Literacy (IMoHL) (Figure 1) and a definition that acknowledges the contextual nature of health literacy and incorporates both medical (individual skills) and public health (interaction between skills and health/social system demands/structures) views. Sorensen et al. (2012) define health literacy as "people's knowledge, motivation and competencies to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course" (p. 3).

Figure 1

Sorensen's Integrated Model of Health Literacy (Sorensen et al., 2012)

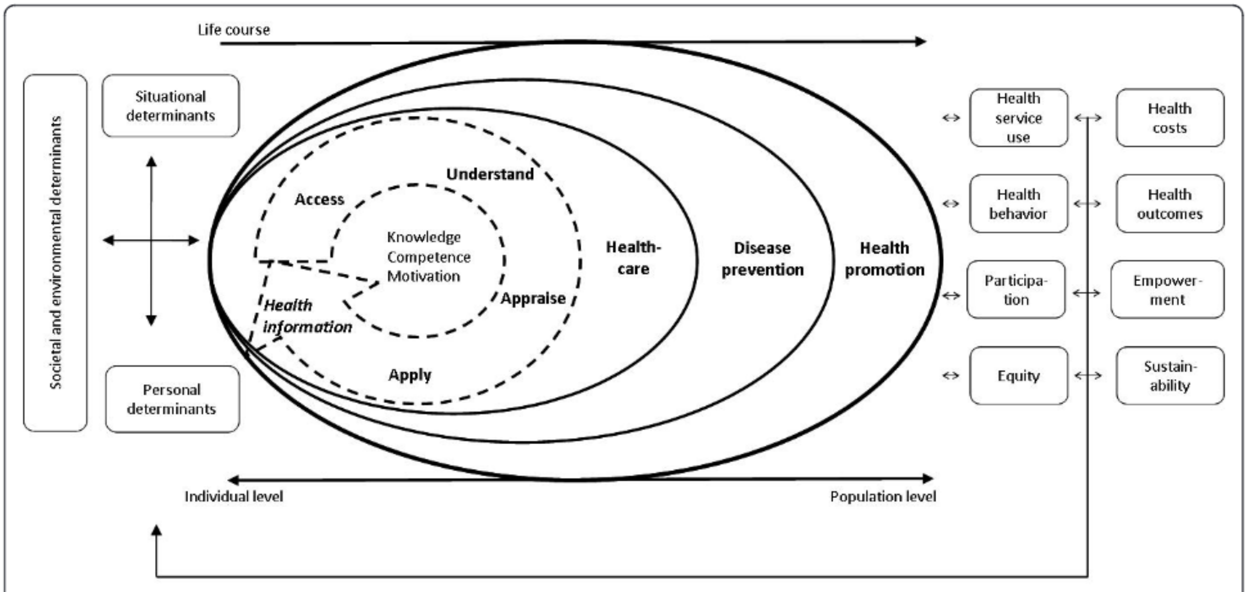

Figure 1 Integrated model of health literacy–see separate file.

Increasingly it is recognized that an individual's level of health literacy is context-specific and inadequate health literacy within any context is consistently associated with poor health outcomes (Nutbeam et al., 2018). The IMoHL suggests both medical and public health views are needed to comprehensively understand health literacy. It suggests individuals must possess knowledge, competence and motivation to engage in the skills required for health literacy (access, understand, appraise and apply) which enables an individual to navigate health within the health care, disease prevention and health promotion domains. The authors incorporate Nutbeam's conception of health literacy (functional, interactive and critical) (Nutbeam, 2000) to consider factors necessary to engage in health literacy skills and suggest interrelated antecedents and consequences to health literacy. The thesis presented in this report applied Sorensen et al.'s IMoHL (Figure 1) to measure health literacy levels and guide the exploration of contextual factors that may be associated with health literacy.

Rationale for Investigating Health Literacy in Minor Ischemic Stroke Survivors

In Canada, as acute ischemic stroke treatment advances and the population ages, more individuals are surviving stroke with minor deficits and returning home directly from the emergency department (ED), Stroke Prevention Clinic(SPC), or after a brief hospitalization (Mountain et al., 2020; Heart and Stroke Foundation, 2017). The risk of stroke recurrence after a MIS is highest within the first month (Kheiri al. 2019; Coull et al., 2004), and 87% of MIS survivors report lingering stroke-related changes at 6 months (Edwards et al., 2006). MIS survivors experience numerous transitions during the first 30 days after stroke and communication breakdown during this time can contribute to them experiencing adverse events (Spencer & Punia, 2021; Ireland et al., 2010). During the high-risk period in the first month after a stroke, MIS survivors must be able to recall or learn skills in accessing, understanding, appraising and applying health information to effectively self-manage many aspects of stroke recovery and secondary stroke prevention. MIS survivors require unique approaches to education and rehabilitation that are often overlooked in clinical practice (Faux et al., 2018).

An NIHSS ≤5 is most frequently used to classify ischemic strokes as minor (Musuka et al., 2015) which make up two-thirds of ischemic strokes (Yakhkind et al. 2016). MIS survivors are usually able to perform the basic activities of daily living (Rozon & Rochette, 2015) and return to the community shortly after their stroke either directly from the ED, acute stroke unit (ASU) or inpatient rehabilitation unit (iRU) (after short duration, high-intensity rehab) (Mountain et al, 2020). It is suggested that patients with an NIHSS ≤5 who have significant impairments in motor or ataxia items on NIHSS may be less likely to return home directly from the ASU than those with similar NIHSS score and deficits in other areas (e.g. aphasia) (Yaghi et al., 2016). It can be difficult to broadly compare minor and severe strokes based on NIHSS because most studies report NIHSS based on a specific clinical cohort of patients diagnosed with stroke (Reeves et al., 2013). In a population-based study, Reeves et al. (2013) found that MIS survivors had similar demographics as those who have experienced a more severe stroke. Age was associated with higher NIHSS, however, the median score in each group was below 5 and differed by only one point between those <65 and those >80 years of age. These findings suggest MIS survivors are likely younger than individuals with more severe stroke; however, many individuals >80 years of age do experience MIS with an NIHSS ≤ 5.

During the first month after a stroke, MIS survivors are at the highest risk for recurrence (Coull et al., 2004) and experience numerous transitions that place them at risk for adverse events (Spencer & Punia, 2021; Ireland et al., 2010). MIS survivors and their caregivers must employ health literacy skills to self-manage the effects of stroke, engage in stroke recovery and prevention strategies and appropriately identify and act on symptoms of a new stroke.

Education is considered a critical factor in MIS care and a key component in supporting self-management of stroke risk factors, health system navigation and stroke recovery (Mountain et al., 2020). Unfortunately, research about how best to educate and support recent MIS survivors has not kept pace with the progress made in acute care treatment of moderate to severe strokes (Olson & Juengst, 2019). Existing services often assume that MIS survivors have adequate health literacy skills to effectively engage in stroke education and self-management (Mackey et al., 2016); however, many MIS survivors report unmet health information needs and challenges accessing relevant services (Green & King, 2007; Edwards et al., 2006). As lower levels of health literacy are associated with higher age (The HLS19 Consortium of the WHO Action Network M-POHL, 2021) and cardiovascular risk (Lindahl et al., 2019), the health literacy skills of many MIS survivors may be inadequate to effectively manage their stroke within the complex context of numerous transitions and personal, situational or societal barriers after stroke.

Research exploring health literacy within the context of recent MIS survivors returning to the community is scarce (Finch et al., 2020; Faux et al., 2018). A deeper understanding of the prevalence and contextual factors associated with health literacy in recent MIS returning to the community is needed to enhance interventions and reduce the risk for adverse events. Research in other fields, suggests that the creation of contextually relevant tailored education and support services can reduce health inequities (Ramos et al., 2013; Campbell & Quintiliani, 2006). The study described in this thesis will address a major gap in understanding the levels of health literacy and health literacy correlates in MIS survivors anticipated to return to the community within the first month after stroke. Understanding the landscape of health literacy in MIS survivors returning to the community within the first month after stroke is critical to developing equity-focused interventions aimed at addressing high unmet health information needs and reducing the risk for poor health outcomes. It is reasonable to suggest that knowledge from the current thesis may be useful in reducing health inequities in this growing population.

Chapter Two: Literature Review

Structured Literature Review of Health Literacy in Stroke

A structured literature review was conducted to better understand the body of research surrounding health literacy in stroke survivors. All categories of stroke survivors were included in the literature review as health literacy research specific to MIS survivors is scarce. The literature review sought to identify primary research studies, literature reviews and quality assurance projects that formally defined or used an accepted measure of health literacy in the stroke population.

After consultation with a McMaster University librarian, an initial structured literature review of health literacy in stroke was performed on June 4th, 2022 of the CINAHL database to inform the proposal for this thesis. A summary of the search is provided in Appendix A with the results in Appendix B. After reviewing the articles for eligibility, 14 were included.

After the completion of this literature review, a systematic review of health literacy and health outcomes in stroke management was published by Aran et al. (2022). Some of the articles identified in the original literature review were included in Aran et al. (2022) systematic review (noted in Appendix B). The articles identified by Aran et al. (2022) were reviewed for eligibility and seven additional articles were identified (Appendix C). One article was a doctoral manuscript, two were conference abstracts with low sample size, two reported on health literacy measures assessed in Taiwanese stroke survivors (SHEAL and computerized adaptive version of HLS-EU-Q47), one was a pilot interventional study and the other assessed readability of stroke information. These findings suggest the original search was fairly comprehensive as only a few additional articles were identified from the systematic review by Aran et al. (2022).

A final structured literature review was conducted on April 23, 2023 as recruitment into the study conducted as part of this thesis was nearly complete. This literature search was conducted to include an additional database and identify new articles published in the past year to provide additional insight that informed the interpretation of the study results. A search of CINAHL and Medline databases using the same search terms and eligibility criteria as the June 2022 search was conducted on April 23rd, 2023 (Appendix D). This search identified an additional 12 articles which are summarized in Appendix E.

Key Findings from the Structured Literature Review

Despite the existence of clinically relevant differences in stroke subtypes (hemorrhagic, ischemic, or TIA) including stroke recovery timelines and treatment (Paolucci et al., 2003), health literacy research in stroke survivors rarely focused on a specific type of stroke. No results were specific to the ischemic stroke population; however one was specific to TIAs (Malstam et al., 2022). Results were obtained from several different countries suggesting health literacy in stroke is a global issue; however, none of the studies were Canadian. Six studies were published in the past year suggesting there may be an increase in interest in this field. Quantitative and qualitative methods were employed and they used a variety of definitions or frameworks. The contextual nature of health literacy was frequently noted, however formal measurement of health literacy with standardized tools was limited. Two studies focused on e-health literacy (Avci et al., 2023; He et al., 2023), one focused on medication health literacy (Yoo et al., 2023), one focused on mental health literacy (Lee et al., 2009), and the remaining articles used a general approach to health literacy.

Health Literacy Measurement Tools

Five studies developed, evaluated, or validated quantitative measures of health literacy (Huang et al., 2020; Huang et al., 2022; Huang et al., 2015; He et al., 2023; Huang et al., 2018); however almost all studies were conducted by the same lead author in Taiwan and the other was conducted in China. The measures that were validated were largely based on the Health Literacy Survey (HLS) instruments (Huang et al., 2020; Huang et al., 2022; Huang et al., 2018) and thus guided by the contextual view of health literacy used by the IMoHL. Among the studies by Huang et al., one study developed and assessed a computerized adaptive version of the HLS-EU-Q47 ((HLS-EU-Q (CAT-EHL)) (Huang et al., 2022), another evaluated the HLS-EU-Q47 (Huang et al., 2018), and a third developed and assessed a battery of three brief measures adaptive to acute, sub-acute and chronic phases of stroke consisting of ten questions each based on the HLS-EU-Q47 (HL-3S) (Huang et al., 2020). The HLS-EU-Q (CAT-EHL) was found to have suitable reliability with a mean test length of 17 questions (Huang et al., 2022). The HLS-EU-Q47 was evaluated by latent trait analysis using Rash modelling and found that all 47 items demonstrated acceptable fit, local independence and negligible uniform and non-uniform differential item functioning between different age and education groups (Huang et al., 2018). HL-3S was found to have adequate construct and Rasch reliability (Huang et al., 2020). Two additional studies were identified that purposefully evaluated or validated other measures of health literacy including an e-Health Literacy Scale (e-HLS) (He et al., 2023) and the Short-from Health Literacy Scale (SHEAL) (Huang et al., 2015). He et al. (2023) reported that the translated eHLS version in China demonstrated acceptable reliability and validity. The convergent and discriminative validity of the SHEAL was found to be adequate however the internal consistency, reliability and ceiling effects needed to be improved (Huang et al., 2015).

Other tools were used to measure health literacy in stroke; however, purposeful validation or evaluation studies were not identified (e.g. REALM, Brief Health Literacy Screen, Newest Vital Sign, s-TOFHLA, etc.). These measures were predominantly functional health literacy measures (e.g. REALM, Brief Health Literacy Screen, Newest Vital Sign, s-TOFHLA); although some studies used other HLS instruments informed by the IMoHL (e.g. HLS-EU-Q16).

These findings suggest that purposeful validation of health literacy measures in the stroke population outside of Asia is severely lacking. The HLS group of health literacy measures appears most useful to measure health literacy in stroke due to their purposeful validation in the stroke population and their foundation in the IMoHL.

Race and Gender Differences in Health Literacy

Three studies assessed disparities between different groups of individuals including Black vs. Hispanic home care recipients (Feldman et al., 2019), Black vs. White outpatients within 1 year of their stroke (Johnson et al., 2017) and Male vs. Female outpatients within 2 years of their stroke (Focht et al., 2014). Hispanic individuals were found to have lower health literacy than Blacks who had lower health literacy than Whites and no difference was observed between genders (Feldman et al., 2019; Johnson et al., 2017; Focht et al., 2014). It is important to note however, that direct comparison of the results between each study is limited due to the different study designs and participant characteristics. Additionally, these studies each used different measures of health literacy including the short form version of the Talking Touchscreen Technology (Health LiTT) (Johnson et al., 2017), Rapid Estimate of Adult Literacy in Medicine (REALM) (Focht et al., 2014) and Chew's Health Literacy Scale (Feldman et al., 2019). All three measures were focused on functional aspects of health literacy and whether the results would be consistent with contextual measures remains unknown. Arguably contextual measures of health literacy that consider how the environment shapes an individual's health literacy may be more important in health disparity research than functional measures. These findings highlight the lack of consensus regarding appropriate health literacy tools for use in the stroke population.

Readability of Stroke Information

Two studies assessed the readability of stroke education materials (Sharma et al., 2014; Supan et al., 2010) and found it to be inadequate. The first study evaluated the first 100 web pages from a Google search of “stroke” using Flesch–Kincaid Grade Level and Flesch–Kincaid and Simple Measure of Gobbledygook (SMOG). The authors found that most websites required major revisions to be consistent with the guidelines (Sharma et al., 2014). Additionally, the authors suggested SMOG should be used as the measure of choice as the Flesch–Kincaid Grade Level underestimates reading difficulty (Sharma et al., 2014). In the second article, the authors assessed the readability of written stroke educational material and found that most material was written at grade seven to college reading level (Supan et al., 2010). The authors attempted to edit the documents to a sixth-grade reading level but found difficulty simplifying some concepts (Supan et al., 2010). These findings reinforce the notion that stroke management is complex and written educational materials may be difficult to simplify, however, efforts should be made to do so. It is possible that although written material may support education initiatives after stroke it may not be the most effective education method and alone it is likely insufficient. Logically, measures of health literacy that focus purely on skills related to reading and understanding text may not be the most effective measures of health literacy in stroke.

Factors Associated with Health Literacy

Ten studies noted associations between health literacy and other variables including: disability (Nguyen et al., 2021), education retention (Sanders et al., 2014), length of hospital stay

(Tian et al., 2018), medication administration (Washington-Nash, 2017), medication adherence (Yoo et al., 2023), medication use and self-efficacy (Appalasamy et al.,2019), physical functioning (Feldman et al., 2019), health-related quality of life (Pham et al., 2022) and depression (Clairmont et al., 2020). Media preference in education interventions was not found to be associated with health literacy (Schriner, 2011).

Patient Experience after Stroke

Four studies used a qualitative approach to explore patient experiences after stroke including: adaptation and subjective well-being (Brunborg & Ytehus, 2014), barriers and facilitators to early stroke care (Nemeth et al., 2016), media preference for education (Schriner, 2011), and opinions about information provision after stroke (Roy et al., 2015).

Brunborg & Ytehus (2014) interviewed nine stroke survivors ten years after stroke using a phenomenological hermeneutic approach. The authors found that personal characteristics, finding new meaningful activities, developing new health habits, social and family networks, economic resources and public assistance promoted positive adaptation and subjective well-being after stroke (Brunborg & Ytehus, 2014). Brunborg & Ytehus (2014) suggest that self-care, health literacy, stamina and a positive way of thinking are characteristics that individuals use to promote positive adaptation and well-being after stroke.

Nemeth et al. (2016) used a qualitative descriptive approach to conduct eight focus groups with a total of 52 recent stroke survivors, family members, and hospital and community-based health care professionals. The authors found that barriers to early stroke care included: a lack of trust in the healthcare system and provider, poor communication, low health literacy and financial limitations. Community-based education and faith as a message of hope were found to be facilitators (Nemeth et al., 2016).

Roy et al. (2015) used a mixed methods descriptive survey embedded in a longitudinal research programme of 19 family members and 23 healthcare providers. The authors found that caregivers report "being overwhelmed initially with information they could not absorb; then later floundering as they had to find their own way through the maze" (Roy et al., 2015, p. 7). Healthcare providers identified language, communication, time constraints and workload as barriers to providing information and many did not assess health literacy or consider that the health information needs of stroke survivors and caregivers may differ (Roy et al., 2015).

The findings of these studies further highlight the important role of health literacy in stroke survivors' and their caregivers' ability to adapt to numerous transitions and effectively manage their health after stroke to promote optimal outcomes. The findings further emphasize the need to use a contextual view of health literacy to better understand associations between health literacy and the environment.

Education and Support Interventions

Five studies assessed education and support interventions after stroke or TIA. These included: a "Care-givers' Guide" (Krieger et al., 2022), a cardiovascular prevention program (Malstam et al., 2022) and video narrative intervention (Appalasamy et al., 2020), an obstructive sleep apnea pamphlet (Donald et al., 2018) and a chronic care model team intervention (Towfighi et al., 2021).

In the "Caregivers' Guide", a specially trained counsellor provided flexible needs-based support to caregivers of stroke survivors for as long as needed over as many sessions as needed. This program was associated with improved psycho-social health, functional and interactive health literacy at the caregiver level (Krieger et al., 2022). The authors did not observe an increase in critical health literacy at the caregiver level; however, counsellors noted an increase

(Krieger et al., 2022). These findings suggest it may be more difficult to create change in critical health literacy and a multidimensional, yet flexible approach may be needed to increase health literacy in stroke survivors.

Malstam et al. (2022) used a grounded theory approach to interview six adults with TIA participating in an occupation-focused stroke prevention program (Malstam et al., 2022). The authors found that incorporating engaging in occupations in prevention programs can contribute to changes in lifestyle (Malstam et al., 2022). The authors recommended that programs consider how contextual factors impact health and occupations when considering the sustainability of the interventions (Malstam et al., 2022). Health literacy was referenced as important for behaviour change; however, it wasn't explored in depth in the study.

In a pilot randomized control study, Appalasamy et al. (2020) compared 60 stroke survivors and 54 parallel controls to assess the feasibility of using video narratives as a way to promote a patient's behaviour change. The intervention was found to be feasible and health literacy was measured using the Newest Vital Sign (Appalasamy et al., 2020). The authors found that 85% of participants had adequate health literacy. The role of health literacy in the intervention or associations with health literacy were not assessed (Appalasamy et al., 2020).

Donald et al. (2018) assessed the effectiveness of a health literacy-informed brief education pamphlet for obstructive sleep apnea OSA using a single group of 26 stroke survivors. Although the authors assessed health literacy as part of the baseline demographics, they did not report how health literacy may have influenced their findings. The pamphlet was found to increase obstructive sleep apnea knowledge and intention to discuss obstructive sleep apnea with the physician (Donald et al., 2018).

Health literacy in relation to knowledge acquisition in stroke survivors is often conspicuous in its absence. For instance, Towfighi et al., (2021) used a randomized control trial design to assess if a community-based chronic care model team intervention improved blood pressure control. The authors hypothesized health literacy would be a mediator to blood pressure control and measured it using a modified version of BRIEF Health Literacy Screening Tool. The authors did not find a difference between the two treatment groups in terms of blood pressure control and an effect mediation analysis of health literacy was not available in the results (Towfighi et al., 2021)

The results of these studies support the notion that while health literacy is considered by some as important in patient education and behaviour change, few studies have assessed the impact of an intervention on health literacy or reported the intervention's effectiveness as it relates to different levels of health literacy. Additionally, as individuals will low health literacy may be more reluctant to participate in research (Livaudais-Toman et al., 2014), many individuals who chose to participate in the studies described in this section are likely to have higher health literacy. Whether the results of these studies apply to those with lower health literacy remains unknown.

Formal Literature Reviews

Two literature reviews were identified that provided a definition of health literacy in their review (Taihorn et al., 2021; Pindus et al., 2018). One literature review was a systematic review and meta-ethnography of stroke survivors' and caregivers' experiences with primary and community healthcare services (Pindus et al. 2018). This review cited Nutbeam et al.'s 1998 definition of health literacy "the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health" (p 357).The authors of the review synthesized 51 studies and identified three key constructs: marginalization by healthcare services, passivity vs. proactivity between health care services and patients/caregivers, and fluidity of stroke-related needs. Issues related to continuity of care, service access and information provision were considered to be drivers of a stroke survivor's and their caregiver's levels of marginalization and tendency to be passive recipients of care. The authors suggested that increasing stroke-specific health literacy and improving continuity of care were needed to support stroke survivors in the community (Pindus et al., 2018).

The second review, that used a definition of health literacy, was a comprehensive integrative review aimed at synthesizing studies investigating educational strategies for stroke prevention (Tarihoran et al., 2021). The authors identified 20 studies related to education strategies for secondary stroke prevention published in the last 10 years (Tarihoran et al., 2021). Of the three main themes and several sub-themes identified, health literacy was a sub-theme in eight of 20 articles. The authors concluded that education has potential to increase health literacy and that understanding a stroke survivor's health literacy may support the tailoring of stroke-related education to patients' specific needs. The authors of this review, however, defined health literacy as "stroke survivor's cognitive capacity and awareness of secondary stroke prevention" (Tarihoran et al., 2021, p.370). Unfortunately, this definition lacks reference to a published health literacy model or conceptualization and fails to recognize the decision-making process, actions, or contextual aspects of health literacy. A full-text review was completed by myself of each "health literacy" article. This full text review revealed that almost all studies focused on a patient's stroke knowledge and did not specifically reference health literacy. Only one of the included studies contained the term "health literacy" and purposefully measured it using an accepted health literacy measurement tool (REALM). This study was an Australian RCT that evaluated the effect of a brief secondary stroke prevention education intervention on behaviour change in 77 stroke survivors (Eames et al., 2014).The authors found that 53% of participants had 9th-grade or above health literacy and did not find a difference in behaviour change between the two treatment arms. The authors did not explore whether a relationship was present between REALM scores and treatment effectiveness. These findings suggest that although health literacy is considered an important factor in stroke education the conceptualization of health literacy is variable and has not been a focus in stroke education literature.

The findings of the literature review conducted as part of this thesis highlight that purposeful research that defines health literacy or uses a specific health literacy measure in stroke survivors, is extremely limited. No studies that included or assessed health literacy were found that were specific to the MIS population. This finding is supported by a recent systematic review of health literacy and health outcomes in stroke management (Aran et al., 2022). Despite a rigorous search strategy, Aran et al. (2022) identified a paucity of literature assessing relationships between education, health literacy and health outcomes. Thus, the results of the literature review underpinning this thesis indicate that additional research on health literacy in the stroke population is warranted. This research is needed as part of a complete response that reduces the risk for poor health outcomes after stroke and health disparities.

Brief Summary of What is Known

This section has highlighted what is currently known based on the selected literature regarding health literacy and stroke in general. It is known that the prevalence of ischemic stroke with mild deficits is increasing due to the aging population and advances in acute stroke treatment (e.g. endovascular therapy). Advance is acute stroke treatment enable individuals who initially present to the hospital with more severe stroke symptoms to return home with mild deficits. Many stroke survivors with mild deficits return to the community shortly after their stroke to manage the effects of stroke and secondary stroke prevention (e.g., new medications, lifestyle changes) at home. The first month after MIS carries a high risk for stroke recurrence and adverse events related to numerous transitions (e.g., ED to ASU to outpatient or inpatient rehabilitation to home, medication changes, adapting to the effects of stroke, lifestyle modifications for stroke prevention, etc.). Low health literacy in older adults and the general stroke population is associated with poor health outcomes. Increasingly, health literacy is conceptualized as a contextual entity that is shaped by both the individual and the environment around them. A limitation of previous health literacy research is the lack of consideration for context in how individuals interact with complex health issues. Few health literacy measurement tools have been evaluated or validated in the stroke population and much of the literature uses functional measures of health literacy.

Brief Summary of the Knowledge Gaps

Knowledge gaps regarding health literacy and stroke are based on a thorough review of the literature. Although education is a critical component of care for MIS survivors and health literacy is essential to self-management, research regarding health literacy in stroke survivors was found to be limited. Importantly, no studies were identified that specifically measured health literacy in the MIS population. In the general stroke survivor population, research on educational interventions was more prevalent, however, this research often failed to define health literacy or use a valid and reliable health literacy measure in the study design. In most studies where a validated measure of health literacy was used, the measure selected by the authors was focused on functional health literacy (e.g., S-TOFHLA) and neglected the interactive or critical aspects of health literacy. Inherently measures of functional health literacy emphasize individual skill (e.g. reading and writing) and disregard the role of context in shaping how those skills are applied in complex health scenarios. Recently, some self-report measures that move beyond functional health literacy have been developed and evaluated in Europe and Asia, using rash modeling. However, validated stroke-specific measures that consider the contextual aspects of health literacy are limited. As the effects of stroke are highly variable and the experience is unique for each individual; there is a need to explore health literacy using a context lens in MIS survivors who return home to self-manage their stroke recovery and prevention of future stroke.

Chapter 3: Methods

This chapter will describe the research question, objectives, study design, conceptual framework, study setting, eligibility criteria, sampling, recruitment strategies, sample size calculations, data collection strategies and tools, data management and quality assurance, statistical analysis and ethical considerations.

Research Question:

This study aimed to determine the level of health literacy in recent MIS survivors returning to the community within 30 days after experiencing a stroke and identify potential contextual factors associated with those health literacy levels. The study was conceptually grounded by the IMoHL (Sorensen et al., 2012) to explore the landscape of health literacy in recent MIS survivors with the following objectives:

Primary Objective:

1. To determine the levels of health literacy in recent MIS survivors who are predicted to return to the community within 30 days post-stroke.
2. To test whether the level of health literacy in recent MIS survivors who are predicted to return to the community within 30 days after experiencing a stroke is different from the level of health literacy in the general population sampled in the Health Literacy Population Survey Project 2019-2021(HLS19S) (The HLS19 Consortium of the WHO Action Network M-POHL, 2021).

Secondary Objectives:

1. To explore relationships between the level of health literacy and contextual factors in recent MIS survivors who are predicted to return to the community within 30 days after experiencing a stroke.

2. To explore whether the number of contextual barriers to health literacy and/or the amount of social support from family and friends is associated with the level of health literacy in recent MIS survivors who are predicted to return to the community within 30 days after experiencing a stroke when controlling for age and gender.

Study Design

This study used a cross-sectional survey to assess the levels of health literacy and associated contextual variables in MIS survivors who were predicted to return to the community within 30 days after experiencing a stroke. Convenience sampling was used to recruit patients through a systematic screening and referral process with the support of stroke physicians, Stroke Navigators, Nurses, Nurse Practitioners (NP) and Clinical Nurse Specialist (CNS). Flexibility in recruitment, consent and data collection methods were built into the study design to meet participants where they were, promote sample diversity and reduce selection bias. To reduce the burden on participants and the potential for data lost to follow-up, data collection occurred at the time of consent unless requested otherwise by the participant. The HLS19-Q12 (Appendix F1) was used to measure health literacy. A contextual factors survey (CFS) and data abstraction from the hospital's electronic medical record were used to assess contextual factors that were predicted to be associated with health literacy(Appendix F2).The CFS is described in greater detail in the data collection tools and rationale section of this paper.

A detailed explanation of the statistical analysis is provided in the corresponding section; however, a brief summary is provided here. To estimate the average health literacy level in recent MIS survivors predicted to return to the community within 30 days, the 95% confidence interval (CI) of the mean total score on the HLS19-Q12 was calculated. This score was then compared to the HLS19-Q12 total score in the general population published in the HLS19S to test the hypothesis that the level of health literacy differed between the two groups. The HLS19-Q12 was also used to categorize the level of health literacy as excellent, sufficient, problematic and inadequate according to the calculations provided by the HLS19 Consortium of the WHO Action Network M-POHL (2022). The proportion of participant responses in each health literacy category was reported with 95% Wald CIs. Descriptive statistics of the HLS19-Q12 scores and contextual factors variables were reported to describe the sample. The total HLS19-Q12 score was treated as a continuous dependent variable for additional hypothesis testing to explore associations with the independent contextual factor variables. Non-parametric tests were used to explore associations between HLS19-Q12 total score (dependent) and the contextual factor (independent) variables. Multiple linear regression (MLR) was used to further explore associations between HLS19-Q12 total score, the number of total barriers to health literacy and the amount of health literacy support from family and friends.

Study Setting

This single-center study took place at a research-intensive teaching hospital located in an urban Canadian city that provides high volumes of tertiary stroke care for the city and surrounding region. This center is typical of other district stroke centers in Ontario; however, it differs from smaller rural community hospitals especially those without integrated stroke services (Appendix I). Ontario provides a publicly funded health care system with support for some of the cost of most medication after the age of 65 through the Ontario Drug Benefit Program (Ministry of Health, 2023). Hamilton is a diverse city with one in four people born outside of Canada (City of Hamilton, 2018). Seventeen percent of Hamilton residents are over the age of 65 and 82% of residents completed high school (City of Hamilton, 2018). Although health literacy rates are not reported for the city itself, a recent survey suggests 47% of Ontarians have low health literacy (Schwartz & Filipov, 2016).

MIS care is complex and involves many specialties and transitions during the first month after a stroke. At the time the study was conducted, patients with possible stroke at this center were diagnosed through two pathways: presenting to the emergency department and transferring to the ASU; or presenting to the emergency department or Primary Care Provider (PCP) with referral to the SPC and seen within 72 hours of the referral. In the ASU, all patients with stroke were assessed by a multidisciplinary team (NP, stroke physician, physiotherapist, occupational therapist, social worker, nursing, and speech-language pathologist) who identified their "Band" for stroke rehabilitation (Appendix I). Minor stroke survivors were classified as Band 6 (no rehabilitation and able to be safely discharged home with community services as needed) or Band 2 (brief high-intensity inpatient rehabilitation before discharge home) and moved quickly through the ASU (average length of stay < 5 days) (Appendix I). On the ASU, the expectation was that all patients receive a printed stroke care binder on admission and a rehabilitation "Band" leaflet at discharge. The stroke care binder contained general information about stroke and the brain, diagnostic interventions for stroke, risk factors, medications, prevention, diet, staff roles and orientation to the ASU. The "Band" leaflet contained health information specific to the anticipated needs of patients classified in the corresponding "Band". Through discussion with hospital staff on the unit before conducting the study, it was identified that personalized education for each patient commonly occurred at the moment (e.g., during physiotherapy assessment); however, it was largely informal, verbal and rarely written down. According to the stroke care pathway (Appendix I) and discussion with the unit staff, stroke survivors classified as Band 6 were discharged home with a scheduled telephone follow-up with the ASU NP in 2-3 weeks and direction to follow up with their FP within 2 weeks. Stroke survivors classified as Band 2 were transferred to an iRU (average length of stay ~8 days); where education related to stroke recovery was intended to be emphasized. After a brief stay on the iRU, stroke survivors classified as Band 2 were discharged home to follow up with their PCP for medical management. Despite collaboration with the SPC CNS and nursing staff, no participants were identified through the SPC pathway. It was anticipated that the number of participants identified through this pathway would be low due to the timelines of the recruitment window and the need for an imaging or neurologist confirmed diagnosis prior to enrolment. During the recruitment window, patients with possible stroke that were seen through the SPC would have been started on stroke prevention strategies, while waiting for additional imaging and a confirmatory diagnosis. If an individual had residual symptoms and a clear diagnosis of MIS at the time of their SPC visit, they were often admitted to the ASU and identified by study recruitment strategies on that unit. All stroke survivors returning to the community were expected to be seen in the SPC for follow-up ~3-4months post-stroke. A schematic of the Hamilton Health Sciences Integrated Stroke Unit Model can be found in Appendix I.

Eligibility and Sampling

In the study setting, an implicit assumption was that recent MIS survivors predicted to return home ≤30days after stroke, had adequate health literacy skills to effectively manage their stroke recovery and secondary stroke prevention to avoid poor outcomes, yet no hard data existed to support this assumption. Thus, this population of MIS survivors was the targeted focus of the current study. This thesis chose to focus on imaging-confirmed MIS to reduce the potential of inadvertently enrolling stroke or TIA mimics (Easton & Johnson, 2022; Nadarajan et al., 2014).Convenience sampling was used to recruit participants who met the following inclusion and exclusion criteria.

Inclusion Criteria

- Recent (≤ 30 days) ischemic stroke (diagnosed by a physician specializing in stroke or confirmed by CT or MRI)
- Age ≥ 18 years
- Mild deficits (NIHSS ≤ 5)
- Predicted to return home ≤ 30 days post-stroke
- Ability to provide informed consent consistent with local policies.

Exclusion Criteria

- Unable to complete study procedures (for informed consent or HLS19-Q12) conducted in English.

Although non-English speaking adults living in North America have been found to have lower rates of health literacy (Hickey et al., 2018), the proportion of English-speaking individuals in Hamilton (74%) is higher than Ontario overall (68%) (City of Hamilton, 2018). If individuals were conversational in English but they could not read or write, efforts were made to support study procedures to be completed verbally.

To promote sample diversity, feasibility and ensure sufficient sample size within a reasonable period of time, participants were recruited in person on the ASU and iRU. The purpose of this recruitment strategy was to optimize a representative sample of all recent MIS survivors who met study inclusion. Although telephone recruitment after hospital discharge was permitted, no participants were recruited in this manner as all participants were identified, approached, consented and enrolled on the ASU or iRU before hospital discharge. Although the sample was limited to a single center, recruitment from multiple units within the center promoted generalizability and relevance of the findings for clinical practice. As the HLS19-Q12 is a general measure of health literacy, the questions in the measure are not specific to an individual care pathway and thus the effect of sampling from multiple units was anticipated to be limited.

Recruitment:

Previous research suggests that individuals with low health literacy may be reluctant to participate in research (Livaudais-Toman et al., 2014) and therefore this study did not rely on individuals to self-refer. Existing relationships and stroke clinician research referral pathways were leveraged so that staff within a patient's circle of care could identify and approach patients who met basic eligibility criteria. In my experience as a research nurse in stroke, this strategy promotes trust and engagement in research. It has been suggested that flexibility in recruitment and data collection combined with simple study procedures and low participation burden may reduce some of the barriers to participation in health research by socially disadvantaged groups (Bonevski et al., 2014). It was anticipated that most participants for this study would be recruited in person however it was recognized that this may not always be feasible due to the short duration of hospitalization or SPC visit and increased use of virtual care post-pandemic. A planned recruitment window of 30 days, using measures that could be completed in person or by phone, illustrates the intentional flexibility of the study design. Ultimately, however, the use of telephone consent and procedures was not required for this study. The selection of a simple and brief tool for measuring health literacy and purposeful survey development, regarding its content and length, aimed to decrease any associated burden on participants.

A recruitment diagram is available in Appendix J. On the ASU, clinicians identified MIS survivors classified as Band 6 and Band 2 during morning rounds and approached them for interest in the study. If the patient was interested, the clinician notified the researcher who followed up with the patient to provide a copy of the informed consent form and a more detailed overview of the study. Participants could choose to provide consent just after reviewing the informed consent form (Appendix K) or take some time to consider participation and the researcher would return at a time convenient to the participant. As banding occurred after a full interdisciplinary assessment, Band determination often occurred in close approximation to the ASU discharge date. If the patient was identified as a Band 2, the researcher followed up with the patient on the iRU once the estimated length of stay was clearer. Approval for the recruitment of participants was obtained from the managers of the respective units as part of the Hamilton Integrated Research Ethics Board (HiREB) approval process (Appendix L).

Sample Size:

The sample size in this study was calculated based on the two primary objectives: determining the level of health literacy in recent MIS survivors who were predicted to return to the community within 30 days post-stroke; and testing whether the level of health literacy in this population is different from the level of health literacy in the general population measured in the HLS19S. The HLS19S was conducted in several countries using the HLS19-Q12 and found a mean total score of 76 and a standard deviation of 22.9 (HLS19 Consortium of the WHO Action Network M-POHL, 2022). This data was used to inform the sample size calculations of the current study.

To determine the level of health literacy, the sample mean and standard deviation were calculated from the total individual scores of the HLS19-Q12 and the population mean was estimated with a 95% CI. To calculate the sample size required for this analysis, the following formula was used with an acceptable error of 10:

$$n = \frac{z^2\sigma^2}{d^2}.$$

n= (1.96^2 * 22.9) / 10^2

n = 21

To test whether the mean total HLS19-Q12 score in the population of interest is different from the mean total score in the general population, the following formula was used with a minimum effect size of the known standard deviation/2, (22.9/2 = 11.45), alpha of 0.05, and beta of 0.1:

$$n = \left[\frac{\left(z_{\alpha/2} + z_{\beta}\right)\sigma}{\mu_1 - \mu_0}\right]^2$$

n = [(1.96+1.28)*22.9/11.45]^2

n = 42

The larger sample size of 42 was selected to ensure an adequate number of participants were enrolled to address both primary study objectives. As the study analyses were built on the total HLS19-Q12 score (which requires ≥ 80% completion of the 12 items (Appendix F1), this sample size reflected the required number of completed HLS19-Q12 measures. It was planned that if a participant completed <80% of the HLS19-Q12, their data would be considered incomplete and an additional participant recruited for replacement. This strategy, however, was not required as all enrolled participants completed at least 80% of the 12 items.

Data from the study institution suggests 630 patients were discharged home from the ASU in 2018 which equates to about 52 stroke survivors discharged home per month. In this study, we anticipated 4 months of recruitment (208 patients) and used a systematic screening process to identify patients who may be eligible. Prior to conducting the study, it was estimated that 15% (31) of potential patients would have hemorrhagic stroke. Of the estimated 177 patients remaining, it was predicted 70% (124) would be identified and approached. Of the 124 participants approached, it was predicted 35% would be ineligible (e.g., no confirmed stroke, unable to complete study procedures, lack capacity for consent, severe aphasia, etc.) (44 patients). Of the eligible patients (80) it was predicted 60% would consent to participate (48 participants). These calculations and considerations suggested it was feasible to recruit a sample of 42 participants in 4 months. It was anticipated that several other studies that were enrolling MIS survivors at the time of the current study would impact recruitment. Approval was obtained from the local principal investigators of each study and HiREB to enable co-enrolment between this study and others on the ASU. Due to the low participant burden and observational design in this study, it was possible to co-enrol participants if the participant was agreeable. This strategy helped to reduce barriers to participation. Although the SPC recruitment pathway was anticipated to provide some support to the study, no participants were identified through this pathway as the majority of MIS survivors were seen through the ASU.

Data Collection Strategies and Tools

In all recruitment pathways, HLS19-Q12 and the CFS were collected at the time of consent unless requested otherwise by the participant. As individuals with low health literacy may be more difficult to reach after hospital discharge, allowances for data collection on the ASU were made to reduce selection bias and the under-representation of individuals with low health literacy. This strategy was intended to limit the number of participants lost to follow-up and reduce the burden on participants associated with multiple calls or contact attempts by the researcher. As the HLS19-Q12 is a self-report measure and used to determine the primary objective, it was collected before the CFS to avoid influence from the CFS. The majority of data collected from EPIC was available from encounters with stroke care providers that occurred within the first 30 days after stroke. An important assumption of most analyses is that the data collected is accurate and the collection process is consistent. Accuracy of data entry and data abstraction from EPIC was supported by the researcher's previous experience in this area and data checking strategies employed in the analysis to identify data entry errors. The HLS19-Q12 has been validated for both in-person interviewing and telephone interviewing methods, which was suitable for this study. The use of an interview approach for both methods promoted data consistency, completeness and quality. Additionally, the interviewer read the following statement to all subjects before collection of the HLS19-Q12, "It is not always easy to get understandable, reliable, and useful information on health-related topics. With the following questions, we would like to find out which tasks related to handling health information are more or less easy or difficult. On a scale from very easy to very difficult, how easy would you say it is …" Before completing the CFS, the researcher then explained, "next we will ask you a few questions to better understand your environment and experience handling information about your health"

HLS19-Q12

Performance-based measures of functional health literacy (e.g., REALM and TOFHLA) were originally developed in the 1990s as screening tools to measure the effectiveness of literacy-based interventions and the association between functional health literacy and poor health outcomes (Okan, 2019). The REALM and TOFHLA are the most widely used health literacy measures in cardiovascular disease research (Elbashir et al., 2019). The TOFHLA and REALM have been shortened for ease of use in the clinical setting (S-TOHLA and REALM-SF respectively) and measure reading comprehension, numeracy skills (TOFHLA) and word recognition (REALM). Although these objective measures are widely used and validated in adult non-stroke populations, they do not capture interactive or critical levels of health literacy (Nutbeam, 2000). Furthermore, these objective measures may be influenced by writing ability, visual acuity, or concentration impairments in the stroke population (Elbashir et al., 2019). Self-report measures of health literacy (e.g., Brief Health Literacy Screen (BHLS)) are also reported in cardiovascular research however these measures may overestimate health literacy due to social desirability bias (Schulz et al., 2022). A recent systematic review of health literacy measures used in cardiovascular research suggests a lack of disease-specific measures in this field (Elbashir et al., 2019).

More recently, the 47-item European Health Literacy Survey Questionnaire (HLS-EU-Q47) as a comprehensive self-report measure of health literacy was created from the IMoHL (Pelikan et al., 2019). The HLS-EU-Q47 was then administered in eight countries: Austria, Bulgaria, Germany, Greece, Ireland, the Netherlands, Poland and Spain (n = 1000 per country, n = 8000 total sample) to characterize the landscape of health literacy in Europe (Pelikan et al., 2019). Since formulation, the HLS-EU-Q47 has been evaluated in stroke patients using Rasch modelling (Huang et al., 2018) and shortened versions (12 questions) have been developed for use in the clinical setting (Finbråten et al., 2018; HLS19 Consortium of the WHO Action Network M-POHL, 2022). The HLS19-Q12 is a shortened version of the HLS-EU-Q47 developed by the HLS19 Consortium of the WHO Action Network M-POHL (referred to hereafter as the HLS19 Consortium) and tested in the HLS19S, a large survey of several European countries. More recently, a stroke phase adaptive self-report measure (HL-3S) built from IMoHL has been developed and validated using Rasch modelling, however, at the time of the current study, it had yet to be validated in English or used outside Taiwan (Huang et al., 2020). Stroke knowledge assessments such as the stroke knowledge test, stroke awareness questionnaire and stroke action test have been developed to assess knowledge and response to stroke symptoms; however, these are not purposefully designed to measure health literacy despite their frequent use in the literature (Gill & Sullivan, 2011).

Upon reviewing the health literacy literature, it was identified that a limitation of traditional health literacy measures was a focus on functional aspects of health literacy without consideration of context. Therefore, this study sought to employ a health literacy measure informed by the IMoHL. Although the HLS-EU-Q47 was assessed in stroke patients, it was too long to be clinically feasible. The creation of the shortened HLS19-Q12 was appealing due to its derivation and strong correlation (r=0.93) with the HLS-EU-Q47 (HLS19 consortium of the WHO Action Network (M-POHL), 2021). This subjective measure aims to assess the difficulty of tasks taking into account personal abilities and contextual factors. The HLS19-Q12 uses a matrix of the 3 domains (healthcare, disease prevention and health promotion) by the four skills of health-related information management (access, understand, appraise, apply) as described in the IMoHL with one specific task for each cell of the matrix. Each of the 3 domains are relevant to optimal wellbeing in MIS survivors who return home within 30 days as they must manage their stroke recovery (healthcare), take steps to prevent future strokes (disease prevention) and adjust to changes in the physical and social environment (health promotion).

The HLS19-Q12 was applied and evaluated using Item Response Theory (IRT) in the HLS19S -a large population survey of 42,445 respondents in 17 European countries using a variety of in-person, telephone, paper and computer-based data collection strategies (HLS19 Consortium of the WHO Action Network M-POHL, 2022). Through this survey, the consortium determined the average general health literacy score overall and across each country and identified 4 categories (excellent, sufficient, problematic and inadequate) based on the HLS19-

Q12 (HLS19 Consortium of the WHO Action Network M-POHL, 2022). A review of the measure showed adequate internal consistency (Average Cronbach Alpha of 0.78), good construct validity (good model fit using the confirmatory factor model) and sufficient one-dimensionality (measuring one latent trait for experienced difficulty of items in the Rash Partial Credit Model) (HLS19 Consortium of the WHO Action Network M-POHL, 2021). In the Partial Credit Model analysis the measure had acceptable Weighted Likelihood Estimate (WLE) and Expected A Posteriori (EAP) reliability coefficients (>0.78) (HLS19 Consortium of the WHO Action Network M-POHL, 2021). Test-retest reliability was not reported in the report (HLS19 Consortium of the WHO Action Network M-POHL, 2021). The HLS19-Q12 was shown to correlate higher with other measures of general health literacy (r=0.93) and less with measures of navigational (r=0.56), communication with health providers (r=0.43), digital (r= 0.53) and vaccination health literacy (r=0.52) suggesting it can discriminately measure general health literacy (HLS19 Consortium of the WHO Action Network M-POHL, 2022). Overall, The HLS19-Q12 was found to have good validity and psychometric properties for 4 modes of data collection (paper-assisted personal interview, computer-assisted personal interview, computer-assisted telephone interview, computer-assisted web-based interview), for several languages, in large (mostly) national samples (HLS19 Consortium of the WHO Action Network M-POHL, 2022). As this measure is newly developed, its use in the stroke population has not been tested; however, the longer HLS-EU-Q47 was evaluated using Rash analysis (Huang et al., 2018).

Contextual Factors Survey (CFS)

The HLS19 consortium also explored associations between general health literacy and a predefined set of potential determinants and outcomes of health literacy in the HLS19S. In this analysis, associations were seen between lower health literacy and lower self-perceived health, lower level in society and financial deprivation (HLS19 Consortium of the WHO Action Network M-POHL, 2021). Higher levels of health literacy were associated with positive lifestyle factors, improved health status and reduced healthcare utilization (HLS19 Consortium of the WHO Action Network M-POHL, 2021). In the current study, the CFS was created to measure contextual factors not captured in the medical record and that may be associated with health literacy in the recent MIS population returning to the community within 30 days. The CFS survey was informed by the IMoHL, findings from the HLS19S, a review of the relevant quantitative and qualitative literature, personal experience of the researcher and consultation with a committee of experienced nursing faculty. A copy of the survey can be found in Appendix F2 with the rationale for each variable provided in Appendix G. Selection of variables for the multiple linear regression analysis was based on understanding potentially modifiable clinically relevant contextual factors such as barriers to health literacy and the amount of support from family and friends. To assess the number of barriers experienced by participants, several options are provided in the survey based on consolidating the antecedents suggested in the IMoHL, barriers identified from the literature review and the experience of the researcher in consultation with the committee members. The CFS also provided opportunity for the participant to self-identify additional barriers. In a study exploring the psychosocial correlates of health literacy in patients with coronary artery disease, the amount of social support from family and friends was found to be significantly associated with health literacy (Ussher et al., 2010). We employed similar wording as the question used by Ussher and colleagues (2010) to assess the amount of social support from family and friends, with a slight modification to include the terms "get, understand, judge and act on" as specified in the IMoHL. The CFS was also reviewed by nursing students and faculty for face validity before implementation.

Data Management and Quality Assurance

A data entry interface was created in REDCap (Harris et al., 2009; Harris et al., 2019) and stored on Hamilton Health Sciences servers. A data-sharing agreement was obtained between HHS and McMaster. As a research nurse I had prior experience in data entry and completed the data entry for this study this myself. A risk-based approach was used where outliers in the dataset were double-checked with the source to confirm data accuracy as described in the statistical analysis. Paper documents were stored in a locked cabinet in a locked office and after successful defence of this thesis will be scanned into the Macdrive for archiving.

Statistical Analysis

Describing the Variables and Checking Data Quality:

To describe each of the variables, mean and standard deviation were reported for continuous variables and percentages were reported for categorical variables (Thabane & Akhtar-Danesh, 2008). Histograms of continuous variables were created to assess data distribution and identify possible outliers that may indicate data entry errors (Thabane & Akhtar-Danesh, 2008). Median and IQR were also reported if an obvious skew was identified in the histogram of the dependent variable (Thabane & Akhtar-Danesh, 2008). Bar graphs were created for categorical variables to assess for major data entry errors. If extreme outliers were identified the data was checked for errors and corrected. If the outlier was accurate it was retained for analysis.

Total responses were calculated for each data point to assess for missing data. If data points were missing the original source was checked for data entry errors and corrected. The number of data points for each variable was reported. It was anticipated that some data could be missing if the participant chose not to respond or it was missing from EPIC. As the calculation of the total HLS19-Q12 score included a pre-defined cut-off of 80% complete data and used a standardization process to determine the total score (Appendix F1), no imputation method was used for participants with up to 20% missing values. If participants had less than 80% complete HLS19-Q12 it was planned that the values would be removed from the analysis as it is not possible to obtain a final HLS19-Q12 score. No participants had less than 80% of the HLS19-Q12 completed. It was planned that if a variable had more than 10% of missing responses, the student would consult with the supervisor as to whether the variable should remain in the analysis; however in practice this was not required. If a variable used in the multiple linear regression was missing data, it was planned that the series mean imputation method in SPSS would be used rather than removing the individual from the analysis. Imputation was chosen for this analysis due to the perceived value in data from the remaining variables for that individual. In practice, however, the variables used in the MLR were complete and imputation was not required. If the variable was not part of the MLR and it was being used to explore trends, no imputation method was used as missing data does not impact the analysis of other variables.

To analyze results from the question "Did any of the following factors make it more difficult to get, understand, judge or use health information related to your stroke", responses were assessed categorically as individual barriers (Y/N), and continuously as barrier indices (# of yes in each index) and total barriers (# of yes overall). If "other" was selected and the participant added additional barriers, these were coded as "yes" and added to the number of "yes" responses. A response of "yes" to none would only be selected in the absence of other "yes" responses and it was coded as 0. Barrier indices were created based on the determinants (personal, situational and environmental) described by the IMoHL in consultation with my supervisor (Appendix H).

If respondents selected "other" and provided additional barriers, these responses were reviewed with the student's supervisor and classified according to consensus.

Primary Objective #1: Estimation of the Level of Health Literacy in Recent MIS survivors who are Predicted to Return to the Community within 30 Days

To determine the level of health literacy in the study population, the total HLS19-Q12 score was calculated for each participant as described in Appendix F1. As the HLS19-Q12 total score ranged from 0-100 it was treated as a continuous dependent variable for the analyses. This method is similar to analyses performed in the HLS19S. This method was preferred over sub-categorizing HLS19-Q12 scores into excellent, sufficient, problematic and inadequate as categorization reduces the granularity of the measure making it more difficult to detect changes in future analyses (Harrell, 2001). The sample mean and standard deviation of the HLS19-Q12 scores were calculated. The sample had a non-normal distribution, however it was sufficiently large (n > 30) to apply the central limit theorem for the estimation analyses. The formula $\overline{x} \pm z_{(1-\alpha/2)}\sqrt{\sigma^2/n}$ was used to calculate the 95% CI of the mean HLS19-Q12 score in recent MIS survivors predicted to return home within 30 days using the sample mean and sample standard deviation (Daniel & Cross, 2013).

To provide qualitative relevance to the HLS19-Q12 scores the proportion of scores classified as inadequate, problematic, sufficient and excellent were also calculated. A 95% confidence around the Wald interval was calculated and reported for each proportion using the formula $\hat{p} \pm z\sqrt{\frac{\hat{p}\,(1-\hat{p})}{n}}$. It is important to note, however, that this is a secondary analysis and the original sample size was not estimated for analyzing proportions.

Primary Objective #2: Hypothesis testing of Mean HLS19-Q12 score

To provide context to the total HLS19-Q12 score, the mean HLS19-Q12 score in the population of interest was tested against the mean HLS19-Q12 score in the general population sampled by the HLS19S to determine if they differed. In the HLS19S, the general health literacy level determined by the mean total HLS19-Q12 score was 76. Therefore, the null hypothesis $H_0 : \mu = 76$ and the alternative hypothesis $H_A : \mu \neq 76$ were tested at the significance level of α = 0.05 using the test statistic $z = \frac{\bar{X} - \mu_0}{\sigma / \sqrt{n}}$ (Daniel & Cross, 2013).

Secondary Objective #1: Exploring Relationships between Health Literacy and Contextual Factors

As quantitative data on contextual factors associated with health literacy in recent MIS stroke predicted to return home within 30 days is scarce, this study explored potential associations between health literacy and individual barriers or contextual factors in this population. Differences in HLS19-Q12 score were assessed between levels of categorical variables and corresponding p-values were reported. As the distribution of HLS19-Q12 scores was found to be significantly non-normal, non-parametric testing was applied. Independent variables were tested with Mann-Whitney U if two categories were present and Kruskal Wallis (and pairwise comparison as indicated) if more than two category levels were present (Daniel & Cross, 2013). Associations between HLS19-Q12 score and continuous independent variables were assessed using the Spearmen's correlation and the corresponding p-value was reported (Daniel & Cross, 2013). Health literacy scores were compared between Band 6 and Band 2 participants to assess whether scores differed significantly between the two pathways and further analyses were required; however, a significant difference was not identified.

Secondary Objective #2: Multiple Linear Regression to Explore Pre-selected Factors Associated with Health Literacy

Multiple linear regression was used to explore whether the total number of contextual barriers related to health literacy and/or level of social support from family and friends was associated with the level of health literacy when controlling for age and gender. Multiple linear regression was chosen to retain the granularity of the continuous dependent variable and it aligned methodologically with analyses completed in the HLS19S assessing social gradient and other health literacy predictors. Backward elimination based on significance ($P \leq 0.1$) was used to develop the final model. Although a formal sample size calculation was not completed for this secondary exploratory objective, a sample of 42 is sufficient to detect large effect sizes with 4 predictors (Green, 1991) and provide an estimate of the explained variance in health literacy which could be used for the design of future studies. The total number of contextual barriers were calculated as the total "yes" responses + additional barriers identified by the participant in the question "Do any of the following factors make it more difficult to get, understand, judge or act on information about your health?" The amount of social support was determined as the response to the question "How much support do you get from friends and family to get, understand, judge or act on information about your health?" The data for the regression analysis was derived from a cross-sectional design and therefore it was not possible to determine causality. The adjusted coefficient of determination (R^2adj) was reported to quantify the amount of variation in health literacy explained by the predictors in the model.

Confidentiality, Safety and Ethical Considerations

This study was conducted in compliance with the protocol, and principles laid down in the Declaration of Helsinki, TCPS II, and all applicable local laws and regulations associated with research conducted at Hamilton Health Sciences and McMaster University. Prior to study initiation, written and dated approval from the HiREB was obtained for the protocol and consent forms. Amendments to the protocol and/or consent form were submitted to HiREB for approval prior to implementation. Amendments developed to address immediate and potential safety hazards to the patients could be implemented immediately with subsequent notification to local IRB/IEC; however, this did not occur during the study. As this study was not interventional and the issues discussed were not considered particularly sensitive, the risk to study participants was considered low. Participants were encouraged to answer all questions; specifically those related to standardized assessments, however at any time, the participant could choose not to answer a specific question without impact on study participation or clinical care. If the participant identified health concerns, they were encouraged to follow up with their PCP or the ASU NP as per the clinical pathway. If the participant felt their concern required urgent or immediate assistance, they would be instructed to call 911 or seek urgent care; however, this service was not required, and all participants were enrolled as inpatients.

A potential breach of privacy is the primary risk for participation in this study. Steps were taken to reduce this risk. All records identifying the patient were kept confidential and, to the extent permitted by the applicable laws and/or regulations, were not made publicly available. Participants were assigned a unique study ID which was recorded on data collection sheets and within the database. The study key linking the study ID and participant remained separate from the database. Paper files were stored in a locked cabinet in a locked office at McMaster University or Hamilton Health Sciences. Data archiving followed the principles of TCPSII and institutional practice. Participation in this study and completion of the study questionnaires were voluntary. As part of the informed consent process, the patients were informed in writing that representatives of the HiREB may inspect their medical records to verify the information collected, however, identifiable information would not be taken off-site. Identifiable data will be retained until the successful defence of the student's thesis. After a successful defence, the identifiable data and study key will be destroyed according to institutional policies. Upon destruction of the study key and identifiable data, the database will become anonymized. The anonymized database will be placed on a research data-sharing platform to promote openness and availability of the data for future analyses.

Chapter 4: Results

This chapter presents the results of the study by first describing the sample, followed by the results of the pre-specified statistical analyses for each of the primary and secondary objectives.

Description of the Sample

All 42 participants were enrolled in the study as inpatients on the ASU or iRU between March and June 2023. Although the study allowed recruitment from the SPC it was challenging to integrate screening and recruitment strategies into existing clinical workflow (e.g. identifying imaging or physician-confirmed MIS within 30 days) and the majority of symptomatic patients diagnosed with stroke were seen through the ASU as expected. On average, data collection occurred 6.7 (SD 5.6) days after stroke and 5.9 (SD 9.0) days prior to hospital discharge. When asked to quantify their level of recovery on a scale of 0-100%, participants reported being on average 64.8% (SD 25.0%) recovered from their stroke at the time of data collection. During their stroke recovery, 33.3% of participants received inpatient stroke rehabilitation and 69.0% received outpatient rehabilitation with or without inpatient rehabilitation. Participants experienced an average of 5 (SD 3) medication changes and 1 (SD 1) new diagnosis (in addition to stroke) at the time of hospital discharge. These findings illustrate that although the stroke was minor, recovery was multifaceted and there is a need for adequate health literacy to optimally adjust and self-manage a variety of health changes after a MIS.

Despite intentional efforts to promote sample diversity through a simple and flexible study design, the sample obtained in the current study were predominantly Caucasian (95.2%) adults who lived at home with family (71.4%) and reported receiving "quite a lot" or a "huge amount" of health literacy support from friends and family (83.3%). Two potential participants, who spoke English as a second language (ESL), indicated that completing study procedures and consent in English, in combination with the effects of stroke, was too challenging for them to meaningfully participate.

Completion of high school was scored as 12 years of education, and each year of formal post-secondary education was added thereafter. On average, participants completed high school with 13.7 (SD 2.3) years of education. Most participants were either retired (57.1%) or working full-time (31.0%) and had a PCP (95.2%). The average age of the sample was 65.7 (SD 14.2) years old and 45.2% were female with 54.8% male. Some older adults were excluded from the current study as they were unable to provide consent or respond to the HLS19-Q12 themselves and proxy (e.g., Substitute Decision Maker) consent or responses were not allowed.

ABCD2 is a secondary stroke risk prediction score used to classify individuals with Transient Ischemic Attack and MIS into high (≥4) and low (<4) risk (Wardlaw et al., 2015). The average ABCD2 score in the current study was 4.2 (SD 1.3) suggesting a relatively high risk of recurrence. In this study, 16.7% of participants had a previous stroke or transient ischemic attack, 16.7% had atrial fibrillation, 31.0% were smokers, 57.1% had hypertension, 42.9% had hyperlipidemia, 26.2 % had diabetes, 14.3% had coronary artery disease and/or myocardial infarction and 85.7% had other medical conditions. Only 2.4% had no pre-existing medical conditions.

Few participants (21.4%) reported receiving written information about their stroke at the time of data collection; however, 92.9% felt they would be able to manage their stroke at home. Although participants felt they would be able to manage their stroke at home, only 59.5% reported that they believed they had received enough information to do so at the time of data collection. Some participants reported that they anticipated additional written information at the time of hospital discharge. Information needs at the time of data collection were related to stroke prevention (66.7%), stroke recovery (64.3%), driving (47.6%), fatigue (42.9%), mental health (31.0%), return to work (31.0%), financial support (23.8%), community programs (23.8%), social relationships (16.7%) and other (11.9%). Most participants reported that they would speak to an HCP (97.6%) for information to get well after their stroke. Other strategies for accessing information after stroke included: educational material from the hospital (61.9%), a family member or friend (50.0%), the internet (47.6%), mass media (14.3%), social media (9.5%) and other (4.8%). Participants reported an average of 6 (SD 3) barriers to health literacy with fatigue being the most prevalent (71.4%) and the timing of information delivery (40.5%) being the second most prevalent.

A more detailed summary of the independent variables and their associations with HLS19-Q12 scores can be found in Tables 1-4. Descriptive statistics (mean, standard deviation) of continuous variables and their correlation with HLS19-Q12 score are provided in Table 1. Questions from the CFS that allowed participants to select more than one response to the question (e.g. where to find information after stroke) were itemized and dichotomized (e.g. internet-yes vs. internet-no) and each response option was analyzed individually. Survey questions that allowed only one response but contained more than 2 options (e.g. employment) were analyzed as a category with more than 2 levels. Table 2 summarizes the proportion of participant responses for each option (Yes or No) of dichotomous variables. The associated HLS19-Q12 score (mean, standard deviation) of participants selecting each response option is also provided and compared using the Mann Whitney U test (Table 2). Table 3 summarizes the proportion of participant responses in each option of categorical variables with more than 2 levels. The associated HLS19-Q12 score (mean, standard deviation) of participants selecting each level is also provided and compared using the Kruskal-Wallis test (Table 3). Table 4 summarizes the prevalence of specific barriers to health literacy as reported by participants (defined as the number of participants responding "yes" that the barrier existed compared to those responding "no"). The associated HLS19-Q12 score (mean, standard deviation) of participants experiencing the barrier (selecting yes) and those not experiencing the barrier (selecting no) is also provided and compared using Mann-Whitney U testing (Table 4).

Table 1

Spearmen correlation of continuous independent variables and total HLS-19 Q12 score

Variable	N	Mean (SD)	Spearman Correlation with HLS19-Q12 total Score (p value)
HLS19-Q12	42	76.3 (21.6)	NA
Total Number of Barriers Reported	42	5.8 (3.3)	-0.374 (0.015)*
Total number of Personal barriers reported	42	2.7 (1.7)	-0.355 (0.021)*
Total number of situational barriers reported	42	1.7 (1.5)	-0.157 (0.321)
Total number of Societal barriers	42	1.5 (1.2)	-0.384 (0.012)*
How much have you recovered from your stroke (0-100)?	41	64.8 (25.0)	0.099 (0.583)
Level of education (years)	42	13.7 (2.3)	0.007 (0.964)
Length of stay	42	10.7 (11.0)	-0.112 (0.482)
Time between the stroke and assessment	42	6.7 (5.6)	0.033 (0.835)
Time between hospital discharge and assessment (0 = day of discharge)	42	-5.9 (9.0)	-0.160 (0.312)
Age	42	65.7 (14.2)	-0.346 (0.025)*
NIHSS	42	1.8 (1.4)	-0.056 (0.723)
ABCD2	42	4.2 (1.3)	0.037 (0.815)
Number of medication changes	42	5.1 (3.2)	0.010 (0.952)
New medical conditions	42	1.4 (1.3)	-0.193 (0.222)

Table 2

Mann-Whitney U test of dichotomous independent categorical variables with total HLS19-Q12 score

Dichotomous independent categorical variable	YES HLS19-Q12 Total Score			NO HLS19-Q12 Total Score			Mann-Whitney test comparing mean rank of HLS19-Q12 Total scores (P value)
	N	Mean	SD	N	Mean	SD	
Where will you look for information to get well after your stroke? (multiple responses allowed)							
Family member or friend	21	73.5	18.1	21	79.1	24.7	0.135
HCP	41	75.7	21.5	1	100	NA^	NA^
Education material from the hospital/doctor	26	78.3	22.1	16	73.1	21.0	0.371
Internet	20	81.4	13.2	22	71. 7	26.5	0.421
Social Media	4	83.5	11.8	38	75.5	22.3	0.648
Mass Media	6	80.7	11.3	36	75.6	22.9	0.942
Other	2	87.5	6.4	40	75.7	21.9	0.529
None	1	100	NA^	41	75.7	21.5	NA^
Stroke Education delivery & readiness for discharge							
Received written information in hospital?	9	81.0	12.4	39	75.1	23.5	0.840
If yes received written info, did you review it?	6						
Do you feel able to manage stroke at home?	39	77.9	20.9	3	55.7	23.7	0.074
Receive enough information to manage your stroke at home?	25	81.5	16.3	17	68.7	26.3	0.112

Dichotomous independent categorical variable	YES HLS19-Q12 Total Score			NO HLS19-Q12 Total Score			Mann-Whitney test comparing mean rank of HLS19-Q12 Total scores (P value)
	N	Mean	SD	N	Mean	SD	
What additional information would you like to receive about your stroke?							
Stroke Prevention	28	76.3	22.9	14	76.3	19.5	0.882
Stroke Recovery	27	72.7	24.0	15	82.9	14.9	0.206
Fatigue	18	78.8	24.7	24	74.4	19.1	0.273
Mental Health	13	70.6	27.3	29	78.9	18.4	0.362
Financial Support	10	63.4	27.2	32	80.3	18.2	0.036*
Social Relationships	7	74.0	17.6	35	76.8	22.5	0.461
Return to work	13	82.2	16.6	29	73.7	23.2	0.269
Driving	20	70.9	23.5	22	81.2	18.9	0.082
Community programs	10	72.6	11.7	32	77.5	23.9	0.138
Other	5	81.8	10.9	37	75.6	22.6	0.798
None	3	94.3	9.8	39	74.9	21.7	0.067
Gender							
Male	23	72.6	25.2	19	80.7	15.7	0.383
Medical History							
Prior Stroke	5	68.4	12.2	37	77.4	22.4	0.145
Prior TIA	2	79.5	17.7	40	76.1	21.9	1.0
Atrial Fibrillation	7	60.7	31.1	35	79.4	18.2	0.100
Smoking	13	78.9	18.8	29	75.1	22.9	0.689
If Smoking – Current	9						
Hypertension	24	73	23.7	18	80.7	18.1	0.273
Dyslipidemia	18	76.9	19.9	24	75.8	23.2	0.979
Diabetes	11	83.4	18.2	31	73.8	22.4	0.172
Coronary Artery Disease	5	70	22.4	37	77.2	21.6	0.386
MI	1	92	NA	41	75.9	21.7	NA
Medical History: Other	36	76.3	22.5	6	76.3	16.9	0.756
None	1	100	NA	41	75.7	21.5	NA

Dichotomous independent categorical variable	YES HLS19-Q12 Total Score			NO HLS19-Q12 Total Score SD			Mann-Whitney test comparing mean rank of HLS19-Q12 Total scores (P value)
	N	Mean	SD	N	Mean	SD	
Outpatient Rehabilitation Received							
Occupational Therapy	24	78.6	16.3	18	73.2	27.3	0.857
Speech Language Pathology	8	66.9	31.0	34	78.5	18.6	0.329
Physiotherapy	5	75.2	17.8	37	76.4	22.2	0.708
Home Care	2	75	11.3	40	76.4	22.0	0.610
Cardiac Rehab	0	NA	NA	42	NA	NA	NA
Other	3	72.3	9.2	39	76.6	22.3	0.372
None	13	77.6	23.3	29	75.7	21.1	0.543
Treatments and Resources							
Participating in another research study	7	64.4	20.2	35	78.7	21.3	0.059
Has a Family Doctor	40	76.6	22.1	2	71	5.7	0.418
Registered for myChart	14	81.6	14.7	28	73.6	24.1	0.424
Received TPA/TNK	2	71.0	29.7	40	76.6	21.6	0.742
Received EVT	6	77.8	15.6	36	76.1	22.6	0.913
Received inpatient rehab	14	69.8	27.8	28	79.6	17.3	0.310
Ethnicity							
White (vs. African American n=1 or Asian n=1)	40	75.9	22.1	2	83.0	0.0	0.929

^The analysis was not performed as the number of participants in one of the two groups was N≤1

Table 3

Kruskal-Wallis test of multiple-level independent categorical variables with total HLS19-Q12 score

Categorical variables with >2 response options	N	HLS19-Q12 Total Score		Kruskal Wallis comparing mean rank of HLS19-Q12 Total scores (P-value)
	N	Mean	SD	
Support from Family and/or Friends to handle health information (Single response)				
No support	2	96.0	5.7	None and Some separate: 0.039*
Some support	5	60.2	13.7	
Quite a lot of support	19	73.8	24.6	None and Some combined: 0.327
A huge amount of support	16	81.9	17.8	
Living situation				
Home alone	10	76.8	20.3	Home alone and Other separate: 0.094
Home with family	30	74.6	22.1	
Other	2	100	0	Home alone and other combined (Mann-Whitney): 0.328
Employment				
Retired	24	69.5	23.4	Unemployed, Stay at home, Part-time Separate: 0.146
Full-time	13	83.5	15.9	
Unemployed	3	89.0	19.0	Unemployed, Stay at home, Part-time combined: 0.033*
Stay at home parent	1	92.0	NA	
part time	1	92.0	NA	

Categorical variables with >2 response options	N	HLS19-Q12 Total Score		Kruskal Wallis comparing mean rank of HLS19-Q12 Total scores (P-value)
	N	Mean	SD	
mRS				
0	3	80.7	26.9	0.810
1	18	78.8	16.5	
2	12	80.0	13.5	
3	9	64.9	34.5	
TOAST Classification				
Large Artery Atherosclerosis	13	77.7	21.8	0.242
Cardioembolism	11	66.0	27.6	
Small Artery Occlusion	3	80.3	4.6	
Stroke of undetermined cause	9	76.1	17.8	
Stroke of determined cause	6	90.5	12.2	

Table 4

Participant reported prevalence of each health literacy barrier and differences in HLS19-Q12 score between participants who experienced the barrier (yes) and those who did not (no) as reported in the contextual factors survey.

Barriers to Health Literacy	Yes			No			Mann-Whitney test comparing mean rank of HLS19-Q12 Total scores (P value)
	N	HLS19-Q12 Total Score		N	HLS19-Q12 Total Score		
		Mean	SD		Mean	SD	
1) Fatigue	30	72.9	22.3	12	84.8	17.6	0.064
2) Language (e.g. ESL)	10	74.3	16.0	32	76.9	23.2	0.410
3) Communication (e.g. aphasia)	14	78.1	18.7	28	75.4	23.2	0.860
4) Hearing/Seeing	16	69.9	25.6	26	80.2	18.1	0.152
5) Memory	8	59.5	29	34	80.3	17.7	0.031*
6) Motivation	16	80.2	15.5	26	73.9	24.6	0.581
7) Multiple health issues	15	69.5	27.4	27	80.1	17.0	0.280
8) Competing demands/time	15	74.5	20.5	27	77.3	22.5	0.549
9) transportation	12	78.6	18.6	30	75.4	22.9	0.902
10) booking time with HCP	7	72.7	20.2	35	77.0	22.0	0.451
11) trusting HCP	11	71.3	28.9	31	78.1	18.6	0.611
12) Healthcare system navigation	6	65.3	18.6	36	78.1	21.7	0.108
13) HCP Continuity	12	62.6	28.1	30	81.8	15.8	0.027*
14) Physical Environment	15	81.7	14.8	27	73.3	24.3	0.365
15) Limited access to health care resources	5	61.6	19.8	37	78.3	21.3	0.067
16) Method of Information delivery	13	70.0	19.6	29	79.1	22. 1	0.095
17) Timing of Information delivery	17	75.1	18.6	25	77.2	23.7	0.474
18) Technology	8	78.1	19.9	34	75.9	22.2	0.782
19) Finances	7	71.4	20.2	35	77.3	22.0	0.355
20) Stigma	4	39.7	28.2	38	80.2	17.0	0.006*
21) other	1	83	NA	41	76.1	21.8	NA

Primary Objective #1: To Determine the Level of Health Literacy in Recent MIS Survivors Returning Home

The level of health literacy was measured as the total score on the HLS19-Q12. All 42 participants completed at least 80% of the HLS19-Q12 to enable accurate total score calculations. No participants were lost to follow up during the time between consent and data collection. The Cronbach alpha for the HLS19-Q12 in this study was 0.88, suggesting the measure had good internal consistency. A 95% CI (69.7, 82.8) of the average total HLS19-Q12 score was calculated from the sample (Mean 76.3, SD 21.6). These results indicate that we are 95% confident that the average HLS19-Q12 score in recent Canadian MIS survivors who are predicted to return home within 30 days post stroke is between 69.7 and 82.8. The authors of the HLS19-Q12 do provide cut-off points to categorize the levels of health literacy (HLS19 Consortium of the WHO Action Network M-POHL, 2022). The results of these calculations are summarized in Table 5, however, it is important to note that the current study was not powered for estimating proportions. These findings suggest that despite a numerically high average total score, 42.9% of scores were within the problematic or inadequate health literacy range. This proportion is slightly less than American data from Sanders and Colleagues (2014) who found that 59% of stroke survivors had marginal to inadequate health literacy at the time of hospital discharge. Importantly, Sanders et al. (2014) enrolled all stroke subtypes, did not report whether participants were discharged home and used a functional measure of health literacy (s-TOFHLA). It is difficult to compare the two samples as they are quite different, however, I am unaware of published health literacy data specific to MIS survivors to which the current results could be compared.

Table 5

Proportion of HLS19-Q12 scores categorized by excellent, sufficient, problematic and inadequate (HLS19 Consortium of the WHO Action Network M-POHL, 2022)

Categorical level of health literacy	N	%	95% CI of the proportion
Excellent	6	14.3	3.7 – 24.9
Sufficient	18	42.9	27.9 – 57.8
Problematic	11	26.2	12.9 – 39.5
Inadequate	7	16.7	5.4 – 27.9
Total	42	100	NA

A histogram of the total HLS19-Q12 scores showed a left skew distribution. This left skew was significantly non-normal as confirmed by both Kolmogorov-Smirnov ($p < 0.05$) and Shapiro-Wilk ($p < 0.001$) tests. This left skew is consistent with findings in the HLS19S and may represent a ceiling effect and limitation of the HLS19-Q12 (Pelikan et al., 2022). As the distribution of HLS19-Q12 scores was not normal, the median and interquartile range were also calculated and reported (M 83, IQR 67 – 92).

Primary Objective #2: To Test Whether the Level of Health Literacy in the Study Population Differs from the Level of Health Literacy in the General Population Sampled in the HLS19S

A one-sample z-test was used to test the null hypothesis that the mean HLS19-Q12 score obtained in the MIS survivor sample (76.3) was equal to that of the general population sampled in the HLS19S (76.0). Although the sample was not normally distributed the sample size was greater than 30 and the central limit theorem was applied. In this analysis, the null hypothesis was not rejected and it was concluded that the level of health literacy in MIS survivors returning home within 30 days is not significantly ($P = 0.93$) different from the general population sampled in the HLS19S.

Secondary Objective #1: To Explore Relationships between the Level of Health Literacy and Contextual Factors in Recent MIS Survivors who have or will Return to the Community within 30 Days After a Stroke

Kruskal-Wallis (Table 3) and Mann-Whitney U (Table 2 & 4) tests were used to assess for differences in HLS19-Q12 total score between levels of categorical independent variables and spearmen correlation (Table 1) was used to assess for correlations between HLS19-Q12 total scores and continuous independent variables. These exploratory secondary analyses provide insight for future research, however, the results should be interpreted with caution as the hypotheses were not determined a priori and the sample size was not powered to conclude these findings. Additionally, the findings are derived from a cross-sectional analysis and causation cannot be determined.

Increasing age was associated with decreasing levels of health literacy ($rho = -0.346$, $p< 0.05$). Lower health literacy was also associated with a higher number of self-reported barriers to health literacy ($rho = -0.374$, $P < 0.05$). This finding is consistent with our hypothesis and aligns with the IMoHL. Upon further analysis, an increased number of personal ($rho = -0.355$, $P < 0.05$) and societal/system barriers ($rho = -0.384$, $P < 0.05$) were associated with lower health literacy, whereas an increase in situational barriers was not significantly associated with health literacy ($rho = -0.157$, $P = 0.321$).

In the current study, 3 of 20 potential barriers (Table 4) showed a statistically significant difference (Mann-Whitney U test, $P < 0.05$) in total HLS19-Q12 scores between those responding yes, (the potential barrier made it more difficult to get, understand, judge or act on information about health) and no (the potential barrier did not make it more difficult). Difficulty with memory ($P < 0.05$), health care provider continuity ($P < 0.05$) and stigma (feeling uncomfortable asking HCPs to explain something you didn't understand) ($P < 0.05$) were significantly associated with lower levels of health literacy. Three additional barriers were associated with lower health literacy (total HLS19-Q12 score) at the 90% confidence level ($P \leq 0.1$) as shown in Table 1. Although finances as a self-reported barrier was not significantly associated with lower levels of health literacy ($P = 0.35$), the need for information on financial support was associated with lower levels of health literacy ($P <0.05$).

The amount of support from family and friends was associated with health literacy ($P <0.05$) when compared across the four levels of this categorical variable individually using the Kruskal-Wallis test (Table 3). In this analysis, those reporting "some support" demonstrated lower levels of health literacy and those reporting "quite a lot" or a "huge amount" of support demonstrated higher health literacy. Interestingly, two patients who responded "no support" also reported high levels of health literacy. Importantly, however, the number of participants in the "some support" (n=5) and "no support" (n=2) was small and thus limits the inferences that can be made regarding the data. Therefore, participants in those two categories were combined into "None/Some Support" (n=7). Once combined, the amount of support from family and friends variable was no longer significant ($P = 0.33$). Overall, it was concluded that based on the current data, the level of social support was not significantly associated with health literacy. A larger sample size may be needed to establish whether health literacy support is associated with health literacy level, as numerically higher HLS19-Q12 scores were observed with each increase in HL support beyond "some" support.

Secondary Objective #2: To explore whether the Number of Contextual Barriers to Health Literacy and/or the Amount of Social Support from Family and Friends is Associated with

the Level of Health Literacy in Recent MIS Survivors when Controlling for Age and Gender.

A summary of the unstandardized beta, corresponding p-values and adjusted R^2 values are provided in Table 6. The reference category of the categorical variables in this multiple linear regression analysis was Male and a huge amount of health literacy support from family and friends. In the first MLR model, all variables were included; however, none were significant ($P \leq 0 .05$). At $\alpha=0.1$level, the total number of barriers to health literacy was significant; however no other variables were significant. In this model, each additional health literacy barrier was associated with a 1.69 drop in total HLS19-Q12 score ($P\leq0.1$). Although gender was the least significant ($P=0.314$), it was retained in the model as a control. The level of health literacy support was the second least significant variable ($P >0.1$), and therefore removed by backward elimination. In the second model, the total number of health literacy barriers remained significant ($P\leq0.1$) and age and gender remained not significant ($P>0.1$). This model is presented as the final model. Age and gender were retained in this final model as control variables. The final model had a slightly higher adjusted R2 value than the first model. These findings suggest that "the amount of health literacy support" variable had minimal impact on the explained variance in HLS19-Q12 scores when age, gender and the number of health literacy barriers are considered. The VIF of all variables in the final model was less than 2, suggesting age, gender and the number of health literacy barriers were not highly collinear.

In this exploratory MLR analysis with a small sample size, it was concluded that an increase in the total number of health literacy barriers was associated with a decrease in HLS19-Q12 scores when controlling for age and gender at $\alpha=0.1$ level but not at $\alpha=0.05$ level. The level of social support was not found to significantly impact HLS19-Q12 scores when controlled for age, gender and the number of health literacy barriers.

Table 6:

Multiple Linear Regression with Backward elimination models

Variable	Model 1 (Initial)		Model 2 (Final)	
	Unstandardized Beta (P value)	Adjusted R2	Unstandardized Beta (P value)	Adjusted R2
None/Some health literacy support	-10.74 (0.252)	0.12	Removed	0.13
A lot of health literacy support	-5.57 (0.426)		Removed	
Number of health literacy barriers	-1.69 (0.094)		-1.82 (0.069)	
Gender (Female)	6.57 (0.314)		7.21 (0.264)	
Age	-0.38 (0.117)		-0.36 (0.129)	

Chapter Five: Discussion, Implications, Strengths and Limitations

This chapter provides an interpretation of the results described in the previous section and discusses factors to consider when interpreting the results. The potential implications for practice, research, policy and education will then be explored and the strengths and limitations presented.

Study Demographics

MIS survivors are typically older than the general population and previous research using the HLS-Q47 found lower levels of health literacy associated with increasing age (Sørensen et al., 2015). In keeping with this tendency, increasing age was associated with lower levels of health literacy in the current study. The mean age of the participants in the current study (65.7 years) is similar to the age reported in previous prospective observational studies (Age: 65.6, Coutts et al., 2008; Age 65.1, Mandzia et al., 2016); however, it differs from Canadian administrative data in MIS survivors (Age: 73, Yu et al., 2022). This observation suggests that barriers may exist for older MIS survivors to participate in observational research such as this study. The younger-than-anticipated average age in our study sample may have contributed to the similar average HLS19-Q12 scores between the current study and the HLS19S. It is possible that other health issues, more prevalent in older MIS survivors (e.g., dementia or impaired cognition), also may limit participation in observational research (Taylor et al., 2012). The proportion of females (45.2%) in the current study was slightly less than that of Canadian administrative data (49.3% female, Yu et al., 2022). As women are more likely to have a stroke later in life than men (Kelly-Hayes et al., 2003), this finding may relate to the younger age of participants in the current study as older female stroke survivors may experience more barriers to participation.

The requirement for participants to provide consent themselves and complete the HLS19-Q12 in English may have unintentionally incorporated an individualistic Westernized view of health literacy into the study and reduced sample diversity. Participants who agreed to participate in this study were primarily Caucasian, had access to a PCP and reported having “a lot” or a “huge amount” of health literacy support from friends and family. Higher amounts of health literacy support were associated with numerically higher health literacy levels in the current study, although the association was not significant. It is also possible that individuals with more support from family and friends may be able to return home earlier (within 30 days) than those with less support and thus represent a large proportion of the participants.

Most study participants had prior experience in managing a health condition. Previous research is mixed as to whether the number of pre-existing medical conditions improves or impairs one's health literacy. In a small sample (n=24), Frey & Adcock (2020) found that stroke survivors with three or more stroke risk factors had significantly higher health literacy; however, larger studies in older adults found associations between low health literacy and the presence of stroke risk factors (Wolf et al., 2007; Lindahl et al, 2020).

Despite attempts to recruit participants who spoke English as a second language, some participants were excluded due to language barriers. Although individuals who spoke English as a second language were approached for the study, some indicated that completing study procedures and consent in English, in combination with the effects of stroke, was too challenging for them to meaningfully participate. The cognitive load of participating in survey-based research may be higher for participants who speak English as a second language due to communication barriers or the need for translation (Reid, 1990). Challenges recruiting individuals with language barriers into research are well documented (Hayley et al., 2017;

Zeidan et al., 2023) and this may be further amplified in stroke research, where changes in cognition and language are common (Muir et al., 2023).

Individuals who spoke English as a second language and chose to participate in the current study had highly supportive family/friends that assisted in translation. Although this study included strategies to promote the recruitment of participants where English was a second language (e.g., simple design and flexible administration of scales) it did not include formal translation services or materials. These resources may be necessary to promote the inclusion of individuals who speak English as a second language and have limited social supports and possibly lower levels of health literacy. In a recent Canadian study conducted across eight stroke centers in Ontario, ischemic stroke survivors who experienced language discordance (requiring translation support to interact with the health care system) had increased odds of multiple stroke risk factors (diabetes, dyslipidemia, hypertension) and worse functional outcomes (Muir et al., 2023). Additionally, in a recent systematic review of the relationship between English language proficiency and stroke outcomes, it was found that English language proficiency was associated with better stroke prevention outcomes including, symptom awareness, anticoagulation maintenance and awareness of medication indication (Clark et al., 2022). It is possible that the current study did not capture the individuals at highest risk for post-stroke complications and / or poor outcomes and thus may limit the clinical implications of these findings.

This study provides a preliminary assessment of health literacy in MIS survivors using a contextual and relational view; however, confirmation of these findings in a larger and more diverse sample is warranted. To better align with the contextual view of health literacy and enhance generalizability, future studies may consider including the involvement of substitute decision-makers, study partners and translators to aid in obtaining consent and completing questionnaires or as proxy for the MIS survivor.

Level of Health Literacy

The similar average HLS19-Q12 score between MIS survivors and that of the general population in the HLS19S was unexpected; however, this may relate to the demographics of the study participants as noted in the previous section. It is also important to consider that the HLS19S, to which the current study results were compared, was conducted in primarily European countries and variation amongst countries was noted (Pelikan et al., 2022). Whether the general population HLS19-Q12 scores obtained in the HLS19S are similar to the Canadian general population is unknown. Ideally, the results of the current study would be compared to the Canadian general population; however, to the best of my knowledge, there are no published reports on the HLS19-Q12 in the general Canadian population. Although the HLS19S used face-to-face interviews, it also used additional methods of data collection that may be less prone to social desirability bias and inflated scores (e.g., computer-assisted web-based interviews and self-administration) than the face-to-face interview method used in the current study.

The current study was not powered to formally compare proportions with the HLS19S; however numerically similar proportions of "problematic" and "inadequate" health literacy were obtained in the current study (26.2% and 16.7% respectively) and the HLS19S (33% and 13% respectively) with a slight shift toward more inadequate health literacy in MIS survivors (Pelikan et al., 2022). These findings suggest that a large proportion of MIS survivors have "problematic" or "inadequate" health literacy.

The HLS19-Q12 used a contextual view to present participants with tasks deemed important for adequate general health literacy as defined by the IMoHL. Participants rate their level of difficulty with completing the task. This task-based approach lends itself to providing clinically meaningful insight into whether participants perceived that they have adequate health literacy to perform tasks to maintain optimal health within their given context. During the HLS19-Q12 interviews with participants, the author observed that some participants rated tasks as easy (high health literacy) based on their belief in their skills and confidence about access to social resources that empowered them to make health-related decisions (e.g. working in a health field). Other respondents, however, appeared to indicate that health literacy tasks were easy, based on a more paternalistic approach to their care (e.g., it is easy because I follow what the doctor tells me to do). This observation is similar to the findings of Gerich & Moosbrugger (2018) who conducted a qualitative analysis of 20 interviews using the 16-item version of the similar HLS-EU. The purpose of their qualitative analysis was to understand the rationale behind respondents' judgement about the difficulty of tasks presented on the HLS-EU. The authors found heterogeneity in individuals reporting high levels of health literacy on the HLS-EU. Some individuals reported high health literacy as it related to high personal and social resources, motivation and competencies to access, understand, appraise and apply health information. Conversely, other participants with low personal health-related competencies reported tasks as easy (high health literacy) due to their trust and positive interactions with the health care system/ HCP (Gerich & Moosbrugger, 2018). These findings suggest that the HLS tools may account for both individualistic and socialized views of health literacy when calculating the overall level of health literacy. This is considered a strength of the HLS tools as it acknowledges the diversity in which individuals can achieve adequate health literacy. For example, western cultures may view health as an individual responsibility; however other cultures may view the health of one individual as a shared responsibility between the individual, family and health care team. Both strategies may be effective in achieving adequate health literacy to manage health conditions. If only one mechanism of achieving adequate health literacy is measured, the results may not represent the full picture of any one person. Using a health literacy measurement tool that perpetuates a purely individualistic view as the primary method to achieving adequate health literacy may further enhance health disparities as it fails to recognize the important role of external forces for some individuals.

Health Information Needs in Minor Ischemic Stroke Survivors

Although relatively few participants recalled receiving written information about their stroke, these results may reflect the timing of data collection and hospital discharge rather than a lack of information provision. Numerically lower health literacy scores were observed in those who responded "no" to "receive[ing] written information", "feel[ing] prepared to manage your stroke at home" and "receive[ing] enough information" than those who responded "yes", however, the difference was not statistically significant ($P > 0.05$). These findings further support the need for clinicians to consider how a patient's health literacy affects the effectiveness of health-related educational interventions after stroke, particularly in preparation for hospital discharge to the community.

Information about stroke prevention was the most prevalent information needed at the time of data collection, suggesting additional information regarding stroke prevention in this high-risk group is warranted. Although stroke prevention, stroke recovery, driving and fatigue were the most prevalent information needs identified by MIS survivors, none were significantly associated with an individual's level of health literacy. Therefore, it is likely that these information needs exist across health literacy levels.

The majority of participants intended to access health information through their HCP to get well after returning home from their stroke. Whether this intention carried through with action or whether barriers existed to accessing this resource after returning home from their stroke was not assessed in the current study.

In the HLS19S, financial deprivation was found to be the most significant predictor of the total HLS19-Q12 score (Pelikan et al., 2022). Although finances as a barrier was not significantly associated with health literacy in the current study, the need for information about financial support was associated with lower levels of health literacy. Although individuals with MIS can return home, many report reduced capacity for driving, interpersonal relationships, holding paid employment and participating in recreational activities during the first few months (Edwards et al., 2006; Rozon & Rochette, 2015). Additionally, 40% of MIS survivors (NIHSS ≤ 3) do not return to work full-time after 12 months (Vlachos et al., 2023). These challenges can add additional indirect costs to the direct costs (e.g., medication, transportation, home accessibility modifications, rehabilitation) associated with stroke which may have a more profound impact on individuals with lower levels of health literacy. As MIS survivors with low health literacy are at a higher risk for poor health outcomes, failure to address the financial implications of MIS, may place MIS survivors with low health literacy at greater risk for health and social disparities after MIS.

Contextual Barriers to Health Literacy

As MIS survivors experience many transitions and interact with many aspects of the health care system during the first month after stroke (Connolly & Mahoney, 2018; Mountain et al., 2020) interventions informed by an individualistic view of health literacy may not adequately prepare or support these individuals. For example, the selection of a model that emphasized only the functional aspects of health literacy would produce results centered on a participant's ability to read, write or use numeracy skills. This strategy neglects external factors (e.g., HCP continuity, stigma, finances) that may have a more profound impact on a MIS survivor's ability to employ adequate health literacy skills for effective self-management (van der Gaag et al., 2022). The current study is unique as it comprehensively and quantitatively explored associations between contextual barriers to health literacy and health literacy levels in Canadian MIS survivors. A range of contextual barriers to health literacy were identified; however, the small sample size limits the conclusions that may be drawn from this exploratory data. This study provides a preliminary assessment of potential critical barriers to health literacy in the MIS population.

The association of memory with the level of health literacy may relate to the cognitive demands of health literacy (Sorenson et al., 2012). This finding aligns with American data on recent stroke survivors suggesting that low health literacy is associated with poor education retention (Sanders et al., 2014) and the fluid cognitive composite of the NIH toolbox cognitive battery (Johnson et al., 2017). Recent research suggests cognition is a mediator of functional outcomes after stroke (Joundi et al., 2023). Health literacy may play a role in this mediating effect as health literacy is known to influence health outcomes. Further research is needed to better understand the relationship between cognition after stroke, health literacy and health outcomes. In recent years, the amount of research in post-stroke cognitive impairment has accelerated (Chi et al., 2023). It may be prudent to include measures of health literacy in such studies.

Although fatigue as a health literacy barrier was not significantly associated with health literacy levels, it was highly prevalent and approached statistical significance ($P = 0.06$).

Previous research suggests health literacy may mediate part of the association between self-regulation of fatigue and health-related quality of life (Pan et al., 2023). Additional research into the association of fatigue and health literacy in recent MIS survivors is warranted.

An increase in the total number of health literacy barriers was associated with lower levels of health literacy when controlling for age and gender in multiple linear regression at the significance level of $\alpha=0.10$. These findings suggest that the barriers selected in the CFS were important to participants' levels of health literacy. These findings align with Sorensen's model of health literacy and demonstrates congruence of the model with patient experience.

Surprisingly the level of social support was not significantly associated with health literacy in this study, despite a general trend to increasing health literacy with increasing support. This finding may relate to the relatively low number of participants responding 'none' or 'some' health literacy support. Future larger studies may consider continuous (rather than discrete) measures of social support that may be more sensitive to detecting associations with health literacy. Standardized measures of social support such as the multidimensional scale of perceived social support may also be useful.

The current study identified that participants who experienced difficulty with HCP continuity or feeling uncomfortable asking HCPs to explain something they didn't understand, were more likely to have low health literacy. This finding is important considering the transition from hospital to home is a high-risk period for adverse outcomes related to disconnected care (Greenwald et al., 2007). The risk of poor health outcomes related to disconnected care may be further compounded in MIS survivors with low health literacy. The findings of the current study suggest high-risk MIS survivors with low health literacy are particularly impacted by gaps in health service continuity and may be at greatest risk for poor outcomes after stroke.

In a recent systematic review and meta-ethnography of the experience of stroke survivors and caregivers accessing community health care resources, Pindus and colleagues (2018) found that a lack of follow-up from a PCP, community or specialist service was common. In the same study, stroke survivors struggled with a lack of continuity of care as it relates to information, health care management and the therapeutic relationship in the community. Smith and Colleagues (2004) reported similar findings in stroke survivors returning home and suggested patients and their caregivers experience difficulty immediately after hospital discharge related to a lack of skills training and lack of follow-up with PCPs (Smith et al., 2004). These findings are concerning as the majority of participants in the current study intended to obtain support from HCPs after leaving the hospital and barriers associated with health care provider continuity were significantly associated with lower health literacy. These findings highlight the contextual nature of health literacy and the need to consider not only the individual but environmental factors when developing patient-centred educational interventions.

The results of this study begin to address a gap in current stroke research related to understanding health literacy and the associated contextual factors in MIS. Through applying Sorensen's IMoHL, this study was able to identify broader factors (e.g., HCP continuity, stigma, the need for information about financial support) in addition to personal factors (e.g., memory) that were associated with lower levels of health literacy. These insights about the nature of health literacy would not be possible if a functional or individualistic view of health literacy, such as those employed by the Rapid Estimate of Adult Literacy in Medicine (REALM), Test of Functional Health Literacy in Adults (TOFHLA) and Newest Vital Sign (NVS), was used to measure health literacy. This preliminary comprehensive exploration of contextual barriers may inform future studies and initiatives aimed at creating a holistic approach to care for stroke survivors transitioning home as recommended by the Canadian Stroke Best Practices (Mountain et al., 2020). Specifically, memory, HCP continuity, finances and stigma (feeling uncomfortable asking an HCP to explain something you didn’t understand) may be important factors to address when designing education and support services aimed at improving outcomes and reducing health disparities after MIS.

Implications for Practice

The health journey of individuals with MIS differs from those with more severe stroke. Individuals with MIS are more likely to return home within 30 days of their stroke and require self-management skills to optimally adjust to life after stroke (Cipriano et al., 2009). Alternatively, individuals with more severe stroke are likely to remain in hospital with additional support over a longer duration for inpatient rehabilitation (Cipriano et al., 2009). Results of the current study suggest that the average health literacy level of MIS survivors is similar to the general population however the prevalence of inadequate or problematic health literacy was high (42.9%). As low health literacy is associated with poor self-management skills (Mackey et al., 2016), these findings raise concerns about the ability of some MIS survivors to effectively self-manage their stroke recovery and prevention strategies upon returning home. The transition from hospital to home is a time of known vulnerability for adverse events and this population mustn't be overlooked when planning stroke education, support services and systems of care (Greenwald et al., 2007).

It is estimated that more than one in five Canadians do not have access to a PCP (Duong & Vogel, 2023). Racialized, low-income and elderly individuals in Canada are most likely to not have a PCP (Duong & Vogel, 2023; Statistics Canada, 2020). The results of this study suggest efforts must be made to ensure that care started on inpatient units is carried through after hospital discharge and MIS have access to and feel comfortable discussing their health questions with care providers who are knowledgeable and supportive.

Results of the current study suggest that it may be possible to achieve adequate health literacy for individuals with more limited personal health-related competencies when HCP continuity and positive provider-patient relationships are in place. These findings align with previous survey-based research in vulnerable uninsured Americans visiting a primary care centre (Kaminura et al., 2020). Kaminura and colleagues (2020) found that health literacy and continuity of care were associated with better patient-provider relationships. Based on their findings, the authors suggested that health literacy can improve when there is a consistent connection with an HCP and patients' feel comfortable asking their provider questions (Kaminura et al., 2020). Individuals with low health literacy and MIS may benefit from integrated care pathways connecting the hospital and community services which may reduce health disparities in this population.

Implications for Research

Further research on the contextual needs of recent MIS survivors with low health literacy is required to promote more equitable systems of support and education for this high-risk group. Issues related to memory, HCP continuity, finances and stigma (feeling uncomfortable asking an HCP to explain something you didn't understand) may be important factors associated with health literacy; however, larger more diverse studies are warranted. Additionally, further research is needed to better understand the contextual influence of the HCP-patient relationship as it relates to levels of health literacy. For example, booking time with or trusting one's HCP was not associated with lower levels of health literacy in the current study; however, HCP continuity was.

Additional research is needed to explore the timelines of patient readiness to receive various types of information after a stroke and whether existing methods of information delivery are aligned with patient needs, particularly in those with low health literacy who may face greater challenges upon returning home. The current study measured the prevalence of receiving written information, preferences for the content of information and perceived preparedness for managing stroke at home, however other methods of information provision and education may be more important for learning in this population such as skill-based active participation (Tarihoran et al., 2021). These methods may be more difficult to measure with quantitative tools and qualitative or mixed method studies may be beneficial to better understand how to adequately prepare MIS survivors with low health literacy to manage their stroke at home after hospital discharge.

Currently, there exists limited longitudinal research to guide the development of interventions for stroke survivors after discharge from the hospital into the community (Pindus et al., 2023). Future studies should consider longitudinal methods that include interviewing participants after hospital discharge; however purposeful strategies for enrolling hard-to-reach socially disadvantaged individuals after hospital discharge should also be integrated into the study design. These individuals may be difficult to reach by telephone and create selection bias in the findings, leaving little understanding about the needs of more vulnerable and marginalized citizens. Co-creation of the study design and procedures with vulnerable individuals may be important for reaching vulnerable individuals who appear likely to benefit from a relational approach to health literacy interventions.

This study provides some insight into the information needs, methods for accessing information, levels of health literacy and contextual factors associated with health literacy in recent MIS survivors. This knowledge may be useful in future research aimed at designing and evaluating education and support programs. This study did not explore the relationship between health literacy and education practices or outcomes after recent MIS and further research is needed in this area.

Implications for Education

Although this study did not explore patient education practices and outcomes in-depth, results about the information needs and information access strategies of MIS survivors may be useful in the design of future education programs. Pindus and colleagues (2018) identified deficiencies in information provision in stroke education as it relates to content, format and timing. Despite the high prevalence of MIS, little research exists about the information needs of recent MIS survivors (Finch et al., 2020). The findings of the current study provide insight for content in MIS education programs and support the notion that individuals with recent MIS have different information needs (e.g., driving, stroke recovery and fatigue as it relates to resumption of home activities) than those with a recent more severe stroke.

Implications for Policy

The results of the current study suggest that the relationship between HCPs and MIS survivors is an important component of promoting adequate health literacy for self-management of stroke recovery and secondary stroke prevention in high-risk individuals. Increasingly, it is recognized that for patients to achieve adequate health literacy to manage health conditions, health literacy must be understood as a shared responsibility with HCPs, patients and the health care system (van der Gaag et al., 2022). HCPs must understand the importance of their role and their responsibility to tailor educational interventions for MIS survivors according to their health literacy to optimize health outcomes. HCP knowledge and education about health literacy are essential to promoting health equity. This has implications for organizations to create practice environments that are conducive to effective educational and support interventions that consider health literacy and promote continuity of care.

The findings from the current study highlight the importance of using a contextual view of health literacy to create health promotion strategies that consider the social determinants of health in education and support service planning. Failure to consider factors such as financial support may create further health disparities as it fails to address the needs of the individuals at high risk for adverse outcomes after stroke.

Study Strengths

Focus on Minor Ischemic Stroke Survivors

It is logical to suggest that during the first month after stroke, individuals with MIS have different needs, readiness for education and care trajectories than individuals with larger strokes (Finch et al., 2020; Faux et al., 2018; Tellier & Rochette, 2009). Yet few health literacy or stroke education studies have made this distinction when defining the sample or reporting results; making it difficult to determine whether study results apply to MIS survivors. (Finch et al., 2020; Tellier & Rochette, 2009). The current study recognized this gap and clearly defined the population of interest as "recent MIS (NIHSS ≤ 5) survivors predicted to return home within one month after stroke" to which the results of the study are applicable. This focus begins to address the paucity of research on health literacy in MIS survivors.

The Integrated Model of Health Literacy

A strength of the current study is its theoretical foundation in Sorensen's IMoHL (Sorensen et al., 2012). This multidimensional model extends beyond traditional views that focus solely on functional health literacy (reading, writing and numeracy), and considers the interaction between context and one's ability to access, understand, appraise and apply health information. Sorensen et al. (2012) break down the model into digestible components with concrete examples of concepts and relationships. For example, the authors suggest specific personal, situational and societal barriers to consider as it relates to the skills necessary for health literacy (Sorensen et al., 2012). The relational view of the IMoHL shifts the responsibility of health literacy from being centered purely on the individual to include HCPs, policymakers and society as a whole. The use of Sorensen's IMoHL enhanced the current study as the findings were not limited to one particular element of health literacy.

Contextual Factors Survey

The use of a contextual view of health literacy in the current study was considered essential to creating knowledge that is clinically meaningful to inform future research, education, practice and policy initiatives. Sorensen's IMoHL enabled the author to create the CFS that comprehensively explored potential personal, situational and societal barriers to health literacy in MIS survivors. The list of potential barriers provided in the CFS was found to be thorough and comprehensive as no additional barriers were identified by participants.

HLS19-Q12 as a measure of Health Literacy

Another strength of the current study was the use of the HLS19-Q12, developed from Sorensen's IMoHL, to measure MIS survivors' general health literacy using a contextual lens. As this questionnaire was relatively simple, brief, and conducted by in-person interview all respondents were able to complete at least 80% of the questionnaire resulting in no missing data. A strength of this measure is that it has been validated in a variety of administration methods including face-to-face paper-assisted personal interviewing. In survey-based research, it is important the participant understands the question and response options to be able to respond appropriately (Schwartz, 1999). These issues may be amplified in stroke research where language barriers (e.g., aphasia) and changes in cognition are common after stroke. The interview method of administration was beneficial to support patient comprehension. Additionally, face-to-face interviewing can promote data completeness, data quality and enable the inclusion of more vulnerable individuals who have limited reading and writing capabilities, such as those who speak English as a second language (The HLS19 Consortium of the WHO Action Network M-POHL, 2021).

Timing of Data Collection

The timing of data collection in the current study was advantageous in terms of researcher accessibility to the study population. This strategy enabled recruitment to occur within study timelines, which is a challenge for many studies (Ferreira et al., 2019). In the researchers' experience, this method enabled access to most of the eligible MIS survivors who were seen through the institution which reduced the potential for selection bias and missing data due to patients being lost to follow-up after hospital discharge.

Study Limitations

Sample size

This study provides a preliminary assessment of health literacy in MIS survivors using a contextual lens; however, confirmation of these findings in a larger more diverse sample is warranted. The sample size limits the conclusions that may be drawn from the exploratory secondary analysis of associations between contextual factors and levels of health literacy. It is possible some associations identified in the current study are due to chance. Alternatively, the lack of statistical significance for other associations may relate to the smaller sample size and highlights the need for further research in this area.

Generalizability

It is important to consider that the estimate of health literacy and its association with contextual factors in this study is derived from a single Canadian center. This single-center was a research-intensive teaching hospital that provides tertiary stroke care using an integrated approach. The results may differ from smaller rural community hospitals especially those without integrated stroke services. Overall, these results may not be generalizable to all MIS survivors and further research is needed to confirm these findings.

Previous research suggests stroke survivors who take part in clinical research may not represent the typical patient admitted to the stroke unit (Busijaet al., 2013). The exclusion of participants who could not complete study procedures conducted in English is a limitation of the current study. This decision was based on the cost of translating the consent form and questionnaires for non-English speaking participants.

HLS19-Q12 as a Measure of Health Literacy

Although the HLS19-Q12 was found to be useful for measuring the contextual aspects of health literacy, it is a subjective measure and may be more susceptible to social desirability bias and inflated scores. Previous research has suggested that a ceiling effect exists for the HLS19-Q12 (The HLS19 Consortium of the WHO Action Network M-POHL, 2022). In the current study, a ceiling effect may have reduced the ability to detect smaller changes in health literacy and the factors associated with those changes in individuals with higher health literacy scores.

The HLS19-Q12 is a measure of general health literacy and whether general health literacy correlates with stroke-specific health literacy and health outcomes in MIS survivors remains unknown. In the current study, many participants noted that the HLS18-Q12 questions were quite general and not specific to their current stroke experience. Currently stroke-specific measures of health literacy are lacking and there is a need for contextual stroke-specific measures of health literacy (Aran et al., 2022).

Contextual Factors Survey

Although the CFS was found to be comprehensive and it was assessed for face validity, it did not undergo a formal validation study prior to its use.

Cross-Sectional Design

Although cross-sectional designs cannot determine causation, this design is helpful for hypothesis generation and exploration of potential causal relationships related to self-management and stroke recovery upon returning to home.

Chapter Six: Conclusion

This study provides a unique insight into the levels of health literacy and associated contextual factors in recent MIS survivors. Currently, there is a paucity of research in this area to guide practice, education and policy interventions (Aran et al., 2022). The research presented in this thesis begins to address these gaps and provides insight on potential strategies and important considerations aimed at reducing health inequities for recent MIS survivors. With the aim of reducing health inequities for recent MIS survivors, the important findings of this study are described below.

Although the average health literacy level was found to be similar to the general population, many MIS survivors experience problematic or inadequate health literacy. Furthermore, a larger number of MIS survivors reported inadequate health literacy in the current study compared to the general population sampled in the HLS19S. As low health literacy is associated with poor self-management (Mackey et al., 2016) and MIS survivors face numerous transitions that place them at risk for adverse events after stroke (Spencer & Punia, 2021; Ireland et al., 2010), MIS survivors with low health literacy should not be overlooked in practice, research, education and policy interventions.

In the current study, a higher number of contextual barriers (societal, situational and personal combined) was significantly associated with lower health literacy. These findings suggest a multidimensional approach is needed to increase health literacy in this vulnerable population. Tools used to measure health literacy in MIS survivors should be grounded in a contextual model or framework.

Results from the current study suggest that feeling comfortable asking an HCP to explain something you didn't understand (stigma), and HCP continuity are likely to be critical contextual factors that impact MIS survivor's health literacy and ability to manage their health. Additional research is needed, however, to confirm these findings. Existing research suggests stroke survivors in the community experience immense challenges related to care continuity (Pindus et al., 2018). These challenges may further amplify health disparities for MIS survivors with low health literacy. Research in other populations suggests that HCP relationships and continuity may be an important factor to increase health literacy in primary care (Kaminura et al., 2020). Further exploration of the role of HCP continuity and stigma in larger samples of MIS survivors is warranted.

In the current study, difficulty with memory was significantly associated with low health literacy. These findings align with previous research that found that stroke survivors with low health literacy retain less information related to post-stroke education than those with higher health literacy (Sanders et al., 2014). Furthermore, existing research suggests cognition is a mediator of functional outcome after stroke (Joundi et al., 2023) and low health literacy has been associated with poor self-management (Mackey et al., 2016). There is a need to better understand the relationship between post-stroke cognitive impairment, memory and health literacy as it relates to outcomes and education practices after a stroke.

Lastly, information about financial support was identified in the current study as a critical information need for MIS survivors with lower levels of health literacy. Information about financial support should be incorporated into stroke education. This need should be addressed or initiated before the individual leaves the hospital to avoid gaps and additional financial burden. Due to the stigma associated with the need for financial support, information should be offered rather than requested and strategies should be built into institutional and government policies.

The results of this study suggest some practice, education and policy implications and provide insight for future research aimed at understanding the prevalence and role of specific barriers to health literacy for individuals with low self-reported levels of health literacy. The results of these studies may help to develop and refine interventions targeted to MIS survivors with low health literacy.

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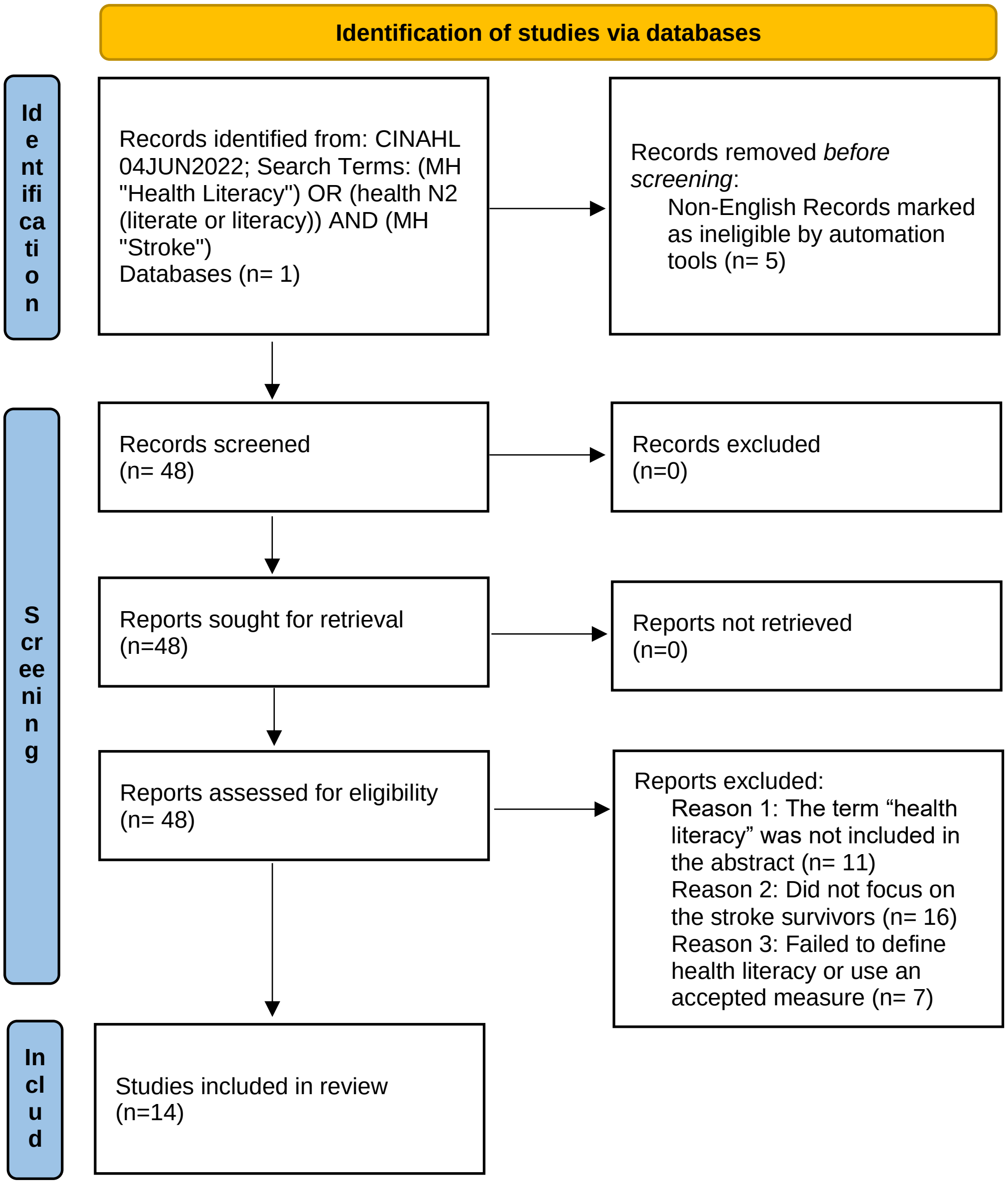
Appendix A

PRISMA flow diagram of search strategy for literature review conducted in June 4th2022 (Page et al., 2021)



Appendix B

Results of the structured literature review of health literacy in stroke on June 4th 2022

Reference	Population Studied, Method used	Key Findings	Strengths/Relevance	Limitations	Health literacy Definition, measure or framework used
Mälstamet al. 2022	N=6. Within 1-15 months of TIA diagnosis and participating in Occupation-focussed stroke prevention programme. Stockholm, Sweden. Grounded theory – Qualitative.	Incorporating engaging in occupations can promote healthy lifestyle habits and health literacy. Contextual factors should be considered when developing and implementing sustainable interventions.	Longitudinal over 12 months.	TIA only. Limited focus on health literacy. excluded people from immigrant backgrounds, people who were not motivated to change, or people who did not have access to technical devices	Health literacy, that refers to both a person's health knowledge and awareness and a person's ability and process to understand and use information to promote, maintain or improve their health

Reference	Population Studied, Method used	Key Findings	Strengths/Relevance	Limitations	Health literacy Definition, measure or framework used
Krieger et al. 2022	Germany. (N=62)First time family care-givers of stroke survivors. Pre–post quantitative questionnaire. Post- qualitative semi-structured interview of caregivers N=30; Post-qualitative interview of counsellors N=11.	Intervention: "The Care-givers Guide" connected caregivers with a specially trained counsellor to provide needs based process oriented support for as long as needed (5-9months) over as many sessions as needed. Results: Caregivers showed improved psycho-social health, functional and interactive health literacy (caregiver perspective) and critical health literacy (counsellor's perspective only).	Quantitatively and qualitatively explored health literacy of caregivers from their own perspective and that of practitioners. Illustrates health literacy can change after intervention. Considered interactive and critical aspects of health literacy.	Deductive approach to qualitatively classify information from respondent into each health literacy domain. No quotes for critical health literacy. Did not use an established or rigorously tested measure of health literacy quantitatively. Only caregivers	Adaptation of Freebody and Luke's health literacy framework: 'functional health literacy' (having enough information to function in day-to-day life) 'interactive health literacy' (having advanced cognitive and literacy skills to participate actively in daily activities and to apply new information to changing circumstances) 'critical health literacy' (most advanced cognitive skills to be used to analyse critically situations and to use this information to have greater control over life)
Tarihoran et al. 2021	integrative review identified 20 articles related to education strategies for secondary stroke prevention published in the last 10 years	This review identifies eight articles within the health literacy subtheme. The authors conclude that education can increase health literacy and understanding the stroke survivors' health literacy may support tailoring education to patients' specific needs	broad search strategy	Focused on stroke knowledge not health literacy. Only one article actually contained the words "health literacy" and purposefully measured it using an accepted tool (REALM).	"stroke survivor's cognitive capacity and awareness of secondary stroke prevention"

Reference	Population Studied, Method used	Key Findings	Strengths/Relevance	Limitations	Health literacy Definition, measure or framework used
Nguyen, et al. 2021	N=951. Cross-sectional study of stroke patients. Vietnam	Health literacy was purposefully measured using HLS-SF12 and demonstrated a mean and SD of 23.4 ± 10.0. Disability was associated with health literacy index in bivariate linear regression analysis (-0.24 <0.001)	health literacy was purposefully measured using HLS-SF12	Health literacy was not a focus of the paper and only used in analysis as a controlling factor	HLS-SF12
Towfighi et al. 2021	N = 487 stroke patients, USA	Systolic BP improved in both intervention and control groups, without significant differences between groups. Health literacy relationship to intervention not reported in results, suggested it is a mediator.	Health literacy included in a priori hypothesis	Health literacy is not a main component of study	Modified version of BRIEF Referenced by authors for selection of HL questions
*Huang et al. 2020	N = 442 stroke patients. Taiwan.	Three scales for health care, disability prevention, and health promotion in the acute, subacute, and chronic phases of stroke, respectively, were developed by a multidisciplinary stroke team. 10 items for each scale.	Stroke specific measure of health literacy	No cut off values provided to determine low health literacy. Taiwan only. Not validated in English	Health literacy can be defined as the individual's capacity to access, understand, appraise, and apply health information and services required to make appropriate health decisions (Sorensen et al., 2012)

Reference	Population Studied, Method used	Key Findings	Strengths/Relevance	Limitations	Health literacy Definition, measure or framework used
Donald et al. 2018	N=26 stroke survivors presenting to the stroke unit. single-center, nonrandomized, single-group, pretest and post-test design.	OSA educational pamphlet written using health literacy concepts improved patient knowledge and intention to discuss OSA screening with a physician	Education resource created from health literacy concepts	No stated definition of health literacy, only focused on reading comprehension	How confident are you filling out forms by yourself? ("Confident with Forms") How often do you have someone help you read hospital materials? ("Help Read") How often do you have problems learning about your medical condition because of difficulty reading hospital materials? ("Problems Reading")
Washington-Nash, 2017	Dissertation, unable to access full text	Reading comprehension had an impact on the ability of a patient to self-medicate correctly. The addition of a nurse-led educational intervention promoted positive health outcomes by ensuring understanding of health education materials	Guided by Orem's Self-Care Deficit Theory		Health literacy is the ability to receive, understand, and act on information intended to help a patient reach optimal medical treatment goals and outcomes

Reference	Population Studied, Method used	Key Findings	Strengths/Relevance	Limitations	Health literacy Definition, measure or framework used
Nemeth et al. 2016	8 focus groups, n=52 total; recent stroke survivors, family members, emergency medical personnel, hospital emergency department staff, primary care providers, and community leaders USA, qualitative descriptive	Barriers and facilitators to early stroke care: six themes: lack of trust in healthcare system and providers; weak relationships fueled by poor communication; low health literacy; financial limitations related to health care; community-based education; and faith as a message of hope. Providers, EMS staff and hospital staff, patients and family members discussed health literacy as a significant problem in the community	Draws connections between participant responses, health literacy and possible impact on stroke outcomes	Highlights low HL as an issue but not how to tailor education	Health literacy is defined as "the degree to which individuals have capacity to obtain, process, and understand basic health information and make appropriate health decisions" (US Department of Health and Human Services, 2000)

Reference	Population Studied, Method used	Key Findings	Strengths/Relevance	Limitations	Health literacy Definition, measure or framework used
Roy et al. 2015	Mixed methods descriptive survey embedded in a longitudinal research programme 'Stroke Families Whānau Programme'. family members' (n=19) and practitioners' (n=23) opinions on information provision post-stroke, New Zealand	Families report being overwhelmed initially with information they could not absorb; then later floundering as they had to find their own way through the maze. Most practitioners did not assess health literacy levels.	Includes family member and practitioner experience. Illustrates challenges of adhering to guidelines in clinical practice and importance of timing/context of information delivery	Did not follow structured mixed methods methodology	"the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions" (Kickbusch, Wait, & Maag, 2005, p. 8)

Reference	Population Studied, Method used	Key Findings	Strengths/Relevance	Limitations	Health literacy Definition, measure or framework used
*Sharma et al. 2014	Google search in 2013, for the term ''Stroke.'' Selected 100 highest ranked Web pages on the basis of Google search ranking and consumer orientation	Readability was assessed using the Flesch–Kincaid Grade Level and Flesch–Kincaid and Simple Measure of Gobbledygook (SMOG). Major text revision required to comply with readability guidelines. The Flesch–Kincaid formula significantly underestimates reading difficulty, and SMOG should be used as the measure of choice	Applied accepted measures of readability	Whether the stroke survivors perform similar searches is not explored	Health literacy is ''the constellation of skills, including the ability to perform basic reading and numerical tasks, required to function in the health care environment'' as defined by the American Medical Association's Ad Hoc Committee on Health Literacy in 1999.
Brunborg & Ytrehus 2014	N=9, 10yrs post stroke, qualitative phenomenological hermeneutical approach,	Factors accounting for adaptation and subjective well-being after the stroke: (1) personal characteristics as the cause of positive adaptation to the new situation, (2) new meaningful activities, (3) new health habits, (4) social networks and family, (5) economical resources and (6) public help.	Considers possible role of HL in long term well being. Provides some evidence of the contextual nature of health literacy	HL is not the pre-stated focus of the study.	Health literacy can be understood as the ability to understand health information and use that information to make good decisions about health and medical care

Reference	Population Studied, Method used	Key Findings	Strengths/Relevance	Limitations	Health literacy Definition, measure or framework used
*Sanders et al. 2014	N=100, USA, prospective cross-sectional study, in-patient stroke unit	59% had inadequate to marginal health literacy. Adequate health literacy w as most predictive of education outcome retention	Define and measure HL and first assessment of its association with education outcomes in stroke	Only used functional HL measure, doesn't consider context or critical/interactive components of HL	S- TOFHLA Health literacy — the ability to obtain, process, and understand health information and services needed to promote better health
Lee et al. 2009	N=214, China, 1 month post stroke, qualitative	Low mental health literacy (Post stroke depression)	Considers the interplay between patient, provider and environment in HL.	No formal measure used to assess health literacy, instead considered depression literate if able to explain depression in own words.	'Health literacy is an achieved level of knowledge or proficiency that depends upon an individual's capacity and motivation to learn and use resources provided by a healthcare system'.

*****Articles that appeared in both this literature review and the systematic review by Aran et al. (2022)

Appendix C

Additional articles identified by Aran and Colleagues systematic review (June, 2022) that met eligibility criteria

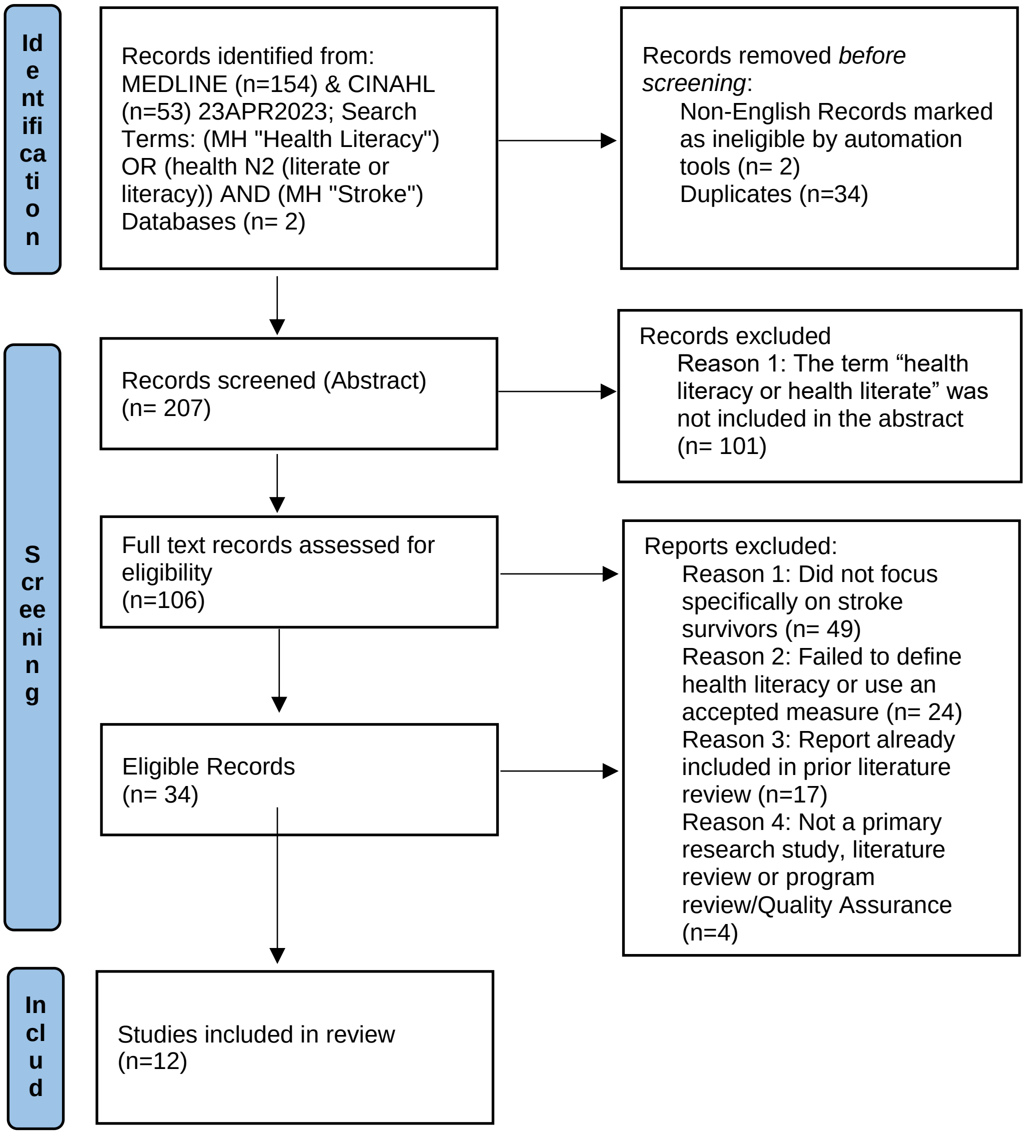
Reference	Population Studied, Method used	Key Findings	Strengths/Relevance	Limitations	Health literacy Definition, measure or framework used
Schriner, 2011	N=30 community-based stroke survivors. Structured interview to determine media preference in education.	Two-thirds of sample at risk of limited health literacy. No statistically significant preference for media type.	Recognized education can be a poor indicator of Health Literacy	Sample Size	individual’s capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions (U.S. Department of Health and Human Services, 2000)
Appalasamy et al. 2020	60 post-stroke Outpatients and 54 controls. Malaysia Assess feasibility and acceptability of RCT of a video narratives intervention	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.	Several other questionnaires about stroke recovery included in study	Low recruitment rate (51%) may be bias. Little reference to health literacy	Newest Vital Sign
Supan et al. 2010	readability of written stroke education material	Majority of stroke education material written at grade 7 to college reading level. Some terms and concepts could not be simplified despite editing.	Highlights challenges in complexity of stroke information and adaptation to appropriate reading level	No participants or qualitative perspectives regarding readability was obtained.	Readability was assessed using a standard score

Reference	Population Studied, Method used	Key Findings	Strengths/Relevance	Limitations	Health literacy Definition, measure or framework used
Huang et al. 2015	N= 87 stroke survivors Taiwan.	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	Validation of health literacy measures in stroke	Small sample size, Taiwan population only.	Mandarin version of SHEAL (short-form Health Literacy Scale) and the Public Stroke Knowledge Quiz (PSKQ) were both administered to participants.
Huang et al. 2022	N=311 stroke patients. Taiwan	Real data simulations were performed to develop a computerized adaptive test of the European Health Literacy Survey Questionnaire.	The adaptive tool demonstrated suitable reliability in all domains with a mean test length of 17 items. More efficient measure of health literacy	Requires computer access to administer	HLS-EU-Q (CAT-EHL) derived from the European Health Literacy Survey Questionnaire
Clairmont et al. 2020	N=24 stroke inpatients. cross-sectional Survey. USA	Patients with more stroke risk factors had lower health literacy. Higher health literacy was associated with higher HAMD scores.	Associations with health literacy in stroke population	Sample size	questions from a modified version of the Stroke Knowledge Test.

Reference	Population Studied, Method used	Key Findings	Strengths/Relevance	Limitations	Health literacy Definition, measure or framework used
Tian et al. 2018	20 male and 10 Female stroke patients admitted to a hospital	67% were determined to have adequate health literacy and 33% had inadequate health literacy. Increase length of hospital stay with inadequate health literacy.	Associations with health literacy in stroke population	Sample size	s-TOFHLA

Appendix D

PRISMA flow diagram of search strategy for literature review conducted in Apr 2023 (Page et al., 2021)



Appendix E

Results of Structure Literature Review April 23rd 2023

Reference	Population Studied, Method used	Key Findings	Strengths/Relevance	Limitations	Health literacy Definition, measure or framework used
Appalasamy et al. 2019	N = 282; <6months post stroke, outpatients; Cross sectional analysis, Malaysia,	Only health literacy was significantly associated with medication understanding and self efficacy (MUSE); HL also associated with medication adherence, 64.5% had adequate health literacy	Large sample size, draws connection between HL and MUSE	Single time point, single center, single time point; functional health literacy only	Newest Vital Sign
Chang et al. 2022	N = 307, inpatients, Cross sectional survey, ischemic stroke, China	36.8% adequate medication health literacy. Education level, annual income, family history of stroke, and number of health problems significantly influenced medication health literacy	Large sample size	medication health literacy not health literacy overall, single time point, single center	“The ability of individuals to obtain and understand information about medications and use this information to use medications in a safe and appropriate manner.” National Library of Medicine of the United States. Medication literacy tool was derived from Sauceda et al. 2012

Reference	Population Studied, Method used	Key Findings	Strengths/Relevance	Limitations	Health literacy Definition, measure or framework used
Avci & Gözüm 2023.	N = 126, Parallel-group blinded assessor, single center RCT; stroke outpatients and caregivers; Turkey	Transitional Care Model based interventions for 13-20 weeks; Followed for 3 months; The intervention group had better caregiver competence, preparation for care, e-health literacy and prevented the progression of burnout	Longitudinal RCT with blinded outcome assessors	Single center, only e-health literacy measured not health literacy;	Norman and Skinner e-Health Literacy Scale
Feldman et al. 2019	N =495; stroke home care patients; cross sectional study; 69.7% were Black; 30.3% Hispanic. USA	Black participants had higher health literacy than Hispanic. Higher health literacy associated with better physical function	Informed by Andersen Behavioral Model; representation of typically under represented populations	Single city, HL wasn't primary focus; no comparison to other ethnicities;	CHEW Health Literacy scale; Brief Health Literacy Screen
Flink et al. 2023	N =108; 12 months post stroke; outpatients; cross sectional study. Sweden	9% had inadequate health literacy, 29% problematic health literacy, and 62% sufficient health literacy; Higher levels of health literacy were associated better depression symptoms, walking ability, perceived stroke recovery, and perceived participation when adjusting for age, sex, and education level	Emphasis on HL; use of a contextual and accepted HL measure	Not longitudinal; can't determine causation in cross-sectional; long duration from stroke to assessment	European Health Literacy Survey Questionnaire (HLS-EU-Q16)

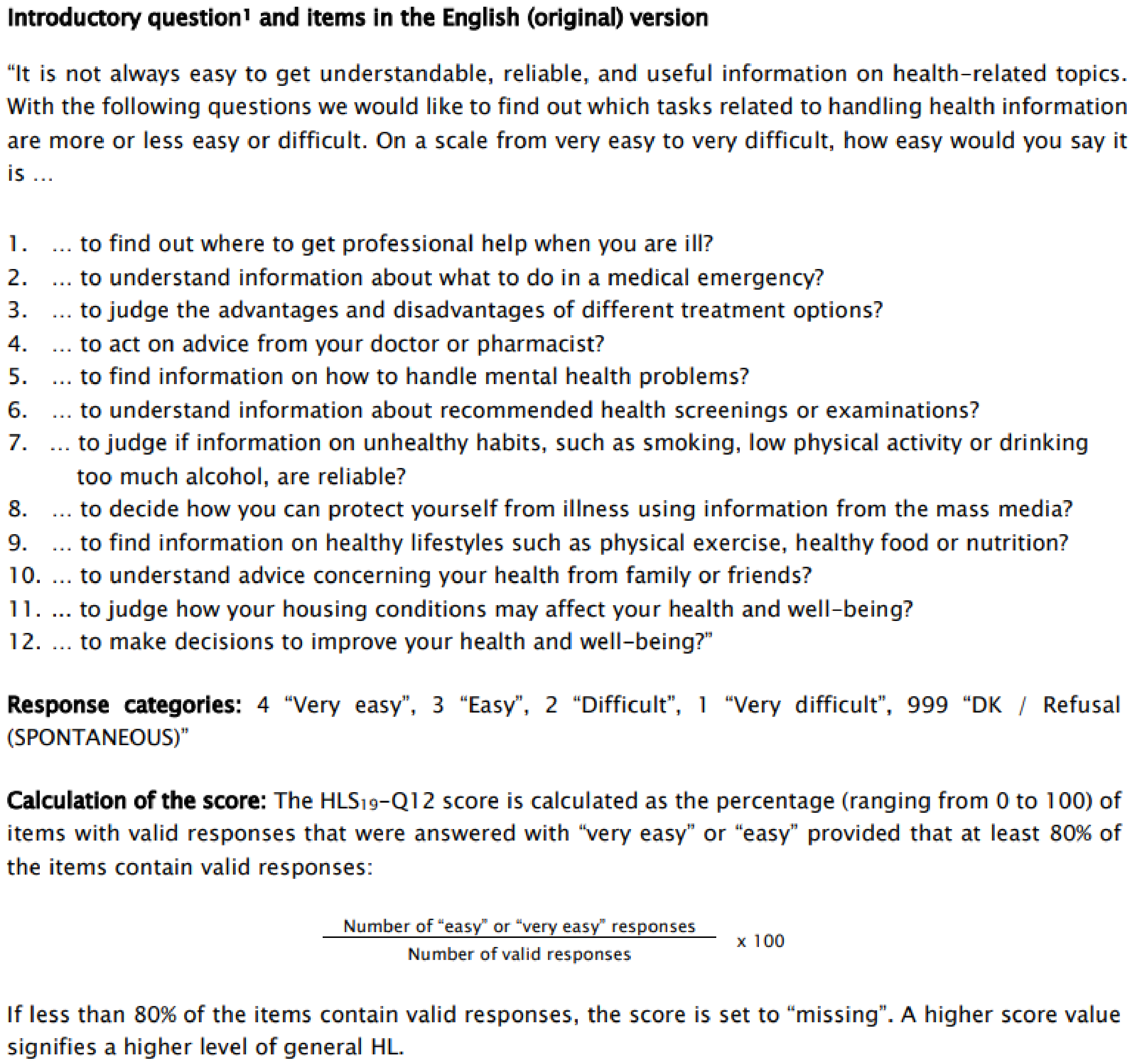
Reference	Population Studied, Method used	Key Findings	Strengths/Relevance	Limitations	Health literacy Definition, measure or framework used
Focht et al. 2014	N = 71, outpatient clinic, stroke within 2 years. USA	No significant gender differences in the recognition of individual warning signs. Women were more likely to recognize all five traditional warning signs compared with men; No difference in HL scores between men and women	Used an accepted measure of HL	Single time point; Functional health literacy measure, long duration since stroke	Rapid Estimate of Adult Literacy in Medicine
He et al. 2023	N=648; ischemic stroke; China; cross sectional; single center	Verified the reliability and validity of the translated version in China. The e-HLS can be used to evaluate electronic health literacy of stroke patients	Large sample size	Single center; "e-health literacy" only	eHealth Literacy Scale （e-HLS) and the eHealth Literacy Scale (eHEALS)
Huang et al. 2018	N = 311 stroke patients. Taiwan; cross sectional	The 12-domain structure of the HLS-EU-Q was adequate in patients with stroke. All 47 items demonstrated acceptable fit, local independence, and negligible uniform and non-uniform differential item functioning between different age or education groups of patients with stroke.	Contextual measure of HL	Single country	European Health Literacy Survey Questionnaire (HLS-EU-Q) 47 item

Reference	Population Studied, Method used	Key Findings	Strengths/Relevance	Limitations	Health literacy Definition, measure or framework used
Johnson et al. 2017	N = 170; USA; 91 Black and 79 white; outpatients; <1 year since stroke; cross-sectional	Black stroke survivors scored lower on health literacy	Provides data on population that is under-represented in research; provides insight on association with cognition	Only measures functional health literacy; requires computer to administer	short form version of the Talking Touchscreen Technology (Health LiTT) assessment (Hahn, Choi, Griffith, Yost, & Baker, 2011; Yost et al., 2010)
Pham et al. 2022	N = 951; Cross sectional survey; Vietnam	Health literacy was associated with health related quality of life	Used a contextual measure of HL	Not focused on health literacy and no definition or model used	HLS-SF12
Pindus et al. 2018	N = 51 studies; Systematic review and meta-ethnography.	51 studies. Concluded that "Stroke survivors and caregivers feel abandoned because they have become marginalised by services and they do not have the knowledge or skills to re-engage. This can be addressed by: (1) increasing stroke specific health literacy by targeted and timely information provision, and (2) improving continuity of care between specialist and generalist services."	Connection of relational aspects associated with health literacy; use a definition of health literacy	Limited articles; interpretation of qualitative studies. Original qualitative studies may not have defined health literacy or used a model	Health literacy encompasses personal skills, ability and motivation of individuals "(. . .) to gain access to, understand and use information in ways which promote and maintain good health" (Nutbeam et al., 1998)

Reference	Population Studied, Method used	Key Findings	Strengths/Relevance	Limitations	Health literacy Definition, measure or framework used
Yoo et al. 2023	N = 537; Korea; multicentre, prospective, longitudinal study	Medication belief, income and health literacy were significant predictors of three-month medication adherence, which predicted one year medication adherence with older age and low income.	Longitudinal, large sample size	Study was not specific to HL; only a functional measure of HL	The Rapid Estimate of Adult Literacy in Medicine-Short Form

Appendix F: Data Collection Tools

Appendix F1: HLS19-Q12



Introductory question[1] and items in the English (original) version

"It is not always easy to get understandable, reliable, and useful information on health-related topics. With the following questions we would like to find out which tasks related to handling health information are more or less easy or difficult. On a scale from very easy to very difficult, how easy would you say it is …

1. … to find out where to get professional help when you are ill?
2. … to understand information about what to do in a medical emergency?
3. … to judge the advantages and disadvantages of different treatment options?
4. … to act on advice from your doctor or pharmacist?
5. … to find information on how to handle mental health problems?
6. … to understand information about recommended health screenings or examinations?
7. … to judge if information on unhealthy habits, such as smoking, low physical activity or drinking too much alcohol, are reliable?
8. … to decide how you can protect yourself from illness using information from the mass media?
9. … to find information on healthy lifestyles such as physical exercise, healthy food or nutrition?
10. … to understand advice concerning your health from family or friends?
11. … to judge how your housing conditions may affect your health and well-being?
12. … to make decisions to improve your health and well-being?"

Response categories: 4 "Very easy", 3 "Easy", 2 "Difficult", 1 "Very difficult", 999 "DK / Refusal (SPONTANEOUS)"

Calculation of the score: The HLS$_{19}$-Q12 score is calculated as the percentage (ranging from 0 to 100) of items with valid responses that were answered with "very easy" or "easy" provided that at least 80% of the items contain valid responses:

$$\frac{\text{Number of "easy" or "very easy" responses}}{\text{Number of valid responses}} \times 100$$

If less than 80% of the items contain valid responses, the score is set to "missing". A higher score value signifies a higher level of general HL.

Appendix F: Data Collection Tools

Appendix F2: Contextual Factors Survey

"Next we will ask you a few questions to better understand your situation and experience handling information about your health"

1. Do any of the following factors make it more difficult to for YOU to get, understand, judge or act on information about your health?
☐ Yes ☐ No Feeling tired or fatigued
☐ Yes ☐ No Language barriers (e.g. English as a second language)
☐ Yes ☐ No Communication Barriers (e.g. difficulty speaking clearly, understanding, reading, writing)
☐ Yes ☐ No Problems seeing or hearing
☐ Yes ☐ No Memory problems
☐ Yes ☐ No Low motivation
☐ Yes ☐ No Other health issues (e.g. Anxiety, managing multiple health conditions)
☐ Yes ☐ No Limited time or competing demands (e.g., household responsibilities, work, care giving responsibilities)
☐ Yes ☐ No Hard to get to and from appointments
☐ Yes ☐ No Hard to book time with my health care provider
☐ Yes ☐ No Hard to trust my health care provider
☐ Yes ☐ No Not always seeing the same health care provider
☐ Yes ☐ No I don't know who to call for information or where to find information or what services are available
☐ Yes ☐ No Limited health care resources available (e.g. Physio, occupational health, etc.)
☐ Yes ☐ No Physical environment of the hospital or clinic (e.g., lighting, noise, privacy, interruptions)
☐ Yes ☐ No How the information was delivered (e.g., medical words, unable to ask questions, it wasn't written down, hard to read, not in person, too complex)
☐ Yes ☐ No Timing of when the information was delivered (e.g., feeling too overwhelmed to process the information at the time)
☐ Yes ☐ No Hard to use the technology used by the hospital, clinic, medical forms, etc. (e.g., MyChart, online forms, fax, electronic education resources)
☐ Yes ☐ No Financial issues (e.g., the cost of medication or health services, other financial responsibilities such as housing or work)
☐ Yes ☐ No Feeling uncomfortable asking doctors or nurses to explain something you don't understand
☐ Yes ☐ No Other: ________
☐ Yes ☐ No I have no difficulty handling health information

2. How much support do you get from friends and family to get, understand, judge or act on information about your health?
☐ No Support
☐ very little support
☐ some support
☐ quite a lot of support
☐ a huge amount of support

3. Where will you look for information to help you get well after your stroke?

- ☐ Family member or friend
- ☐ Educational material given to me in hospital
- ☐ Social media (e.g., facebook, twitter, etc)
- ☐ Mass media (e.g., news)
- ☐ Healthcare provider
- ☐ Internet (e.g., google)
- ☐ Other: _______

4. Have you received any written information about your stroke from the hospital staff?
☐ Yes ☐ No

If yes, did you review it?
☐ Yes ☐ No

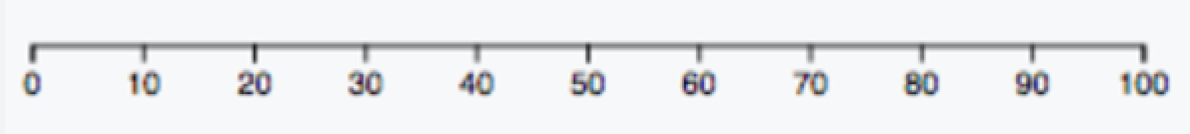
5. Do/did* you feel able manage your stroke at home?
☐ Yes ☐ No
*interviewer selects based on whether patient is currently at home or in hospital at the time the interview is collected.

6. Do you have enough information to care for yourself at home after your stroke?
☐ Yes ☐ No

7. What additional information would you like to receive about your stroke?

- ☐ Stroke prevention
- ☐ Financial support
- ☐ Return to work
- ☐ Driving
- ☐ Stroke recovery
- ☐ Social relationships after stroke
- ☐ Fatigue after stroke
- ☐ Mental health after stroke
- ☐ Programs in my community for stroke survivors
- ☐ Other: ____________

8. On a scale of 0-100, how much do you feel that you have recovered from your stroke?
Where: 0 = no recovery 100 = full recovery.



9) What is your highest level of education? ________________ years
10) Ethnicity:_________

Appendix F: Data Collection Tools

Appendix F3: Data Collection Form

Subject Number: ____________

Date of data collection: __________ Mode of data collection ☐ In person ☐ Telephone

☐ Complete the HLS19-Q12

☐ Complete the Contextual Factors Survey

☐ Collect data from EPIC (below):

Date of Stroke: _________ Hospital length of stay (days): __________

Care pathway: ☐ Band 6 ☐ Band 2 or 3 ☐ SPC

Received inpatient rehabilitation? ☐ Yes ☐No

If yes, Inpatient Rehabilitation length of stay (days): ______________

Length of time between discharge date and study assessments (days):___________

Length of time between stroke onset and study assessments (days):___________

Age: _______ Gender:☐ Male ☐Female ☐ Other________

First 3 digits of postal code: _________

Living Situation: ☐ Home, alone ☐ home, with family ☐ Other:________

Employment Status: ☐ Retired ☐ Stay at home parent ☐ Full-time employment ☐ Part-time employment ☐ Unemployed ☐Other: ________

Registered for my chart in EPIC ☐ Yes ☐No

Referred to cardiac rehab for risk factor control ☐ Yes ☐No

Received TPA or TNK : ☐ Yes ☐ No Received EVT: ☐ Yes ☐No

Most recent NIHSS at the time of study enrollment: ________

Most recent mRS at the time of study enrollment:____________

Medical History (Stroke Risk Factors):

☐ Prior Stroke ☐ Obesity ☐ Other:_______

☐ Atrial Fibrillation ☐ Smoking (Current, former, never) ☐ Hypertension

☐ Hypertension ☐ Dyslipidemia ☐ Diabetes ☐Coronary artery disease

☐ Myocardial Infarction ☐ Prior stroke ☐ Prior TIA

ABDC2 Score: __________

Cause of Stroke (TOAST):

☐ large artery atherosclerosis
☐ cardioembolism
☐ small artery occlusion
☐ stroke of other determined cause: ______
☐ stroke of undetermined cause
☐ Not Reported

Location of Stroke: _____

Referred for outpatient or in home rehabilitation therapy?

☐ Yes, OT ☐ Yes, SLP ☐ Yes, PT ☐Yes, Home care (nursing)

☐Yes, cardiac rehab for risk factor control ☐Yes, Other:_______ ☐No

Referred for nursing home care? ☐ Yes ☐ No

Is the patient enrolled in another research study? ☐ Yes ☐ No

Received follow up with Nurse Practitioner or Family Physician after returning to the community? ☐ Yes ☐ No

Has a Family Doctor? ☐ Yes ☐ No - ☐ Information not available

Number of 30 day Emergency Department revisits and/or readmissions: ______- or ☐ Information not available

Number of medication changes after stroke (new, dose adjustment, discontinued): __________

New medical conditions diagnosed during the stroke encounter (Other than ischemic stroke, list):__________________________________

Appendix G:

Independent Variable Rationale

Variable	Rationale
Age	Control Variable; In Canada, it is suggested that 88% of individuals over 65 have inadequate health literacy (Public Health Association of British Columbia, 2012.). Personal determinant in IMoHL (Sorensen et al., 2012).
Gender	Control variable. Gender is only very weakly associated with HL (higher in females) in general population in HLS19S (The HLS19 Consortium of the WHO Action Network M-POHL, 2021). Personal determinant in IMoHL (Sorensen et al., 2012)
Level of education	Increased HL with level of education in HLS19S general population (The HLS19 Consortium of the WHO Action Network M-POHL, 2021). Personal determinant in IMoHL (Sorensen et al., 2012).
Employment status	Employment status was associated with health literacy in a population study (Šedová et al., 2021)
First 3 digits of postal code	Geographic disparities in cardiovascular disease exist in Hamilton, ON (Christopher, 2022).
Time from stroke to data collection	Quality assurance to ensure participants met eligibility.
Location of survey	Data quality assurance. In person vs. telephone. HLS19-Q12 was administered both in person and telephone in the European Health Survey and found to be valid (The HLS19 Consortium of the WHO Action Network M-POHL (2021).
Care pathway	Data quality assurance to assess for major differences between SPC, Band 6 and Band 2 participants and possible impact on generalizability.
Medical History (Stroke risk factors)	In the elderly, low health literacy is associated with known stroke risk factors (Wolf, Gazmararian & Baker, 2007; Lindahl et al, 2020). Low health literacy was independently associated a high level of CVD risk scores (Framingham risk score) in Swedish population with one CVD risk factor (Lindahl et al, 2020). Another study found higher HL in stroke patients with 3 or more stroke risk factors compared to those with 2 or more (low sample size) (Clairmont, Frey & Adcock, 2020); individuals with limited health literacy are less likely to recognize elevated blood pressure, relapse on smoking cessation, be overweight and experience complications of diabetes which are all known risk factors and targets of secondary stroke prevention education (Magnani et al., 2018
NIHSS	Confirm eligibility; Functional impact of the stroke can impair access to information Eames et al., 2010
mRS at hospital D/C or SPC visit	Functional impact of the stroke can impair access to information Eames et al., 2010
Received TPA or EVT	Describe the population. Standard treatment in stroke care captured in stroke studies.

Variable	Rationale
Cause of stroke TOAST	Standard classification system used in stroke studies. Low health literacy was independently associated with carotid artery plaques in Swedish population with one CVD risk factor (Lindahl et al, 2020)
Stroke location	Describe the population
Referred to outpatient therapy?	Describe the population and supports.
Referred to outpatient cardiac rehab?	Describe the population and supports. Possible under-utilized local service to support risk management and education after returning home (researcher experience)
Preventative service compliance (GP, NP visit)	Low HL is associated with decreased use of preventative services in the elderly (Ferguson & Pawlak 2011).
Hospital length of stay	In the general stroke population, low health literacy is associated with longer hospital length of stay (n=20 sample size) (Tian et al., 2018)
Living situation	Societal determinant in IMoHL (Sorensen et al., 2012). Describe the population and supports.
30 day ER revisits and readmissions	Low health literacy associated with 30-day re-hospitalization in the elderly (Mitchell, Sadikova, Jack, & Paasche-Orlow, 2012) and 30-day readmission in stroke (Bushnell et al., 2013)
Social support from family and friends	Situational determinant in IMoHL (Sorensen et al., 2012) Situational determinant); that individuals with low HL often receive important HL support from a significant other (Edwards et al., 2015). Patients with coronary heart disease reporting less social support from family and friends for discussing their health problems had significantly lower REALM scores (Ussher et al., 2010
Information Sources	In the general population looking for stroke information, the most common source was internet (Bártlová et al. 2021); however internet sources have poor readability (Aran et al., 2022)
Barriers - Fatigue	Qualitative research suggests stroke impairment impedes information access (Eames et al., 2010) and may impact motivation which is a key attribute for HL (Sorensen et al., 2012).
Barriers – communication	Qualitative research suggests communication impairment impedes information access (Eames et al., 2010; Roy et al., 2015)
Barriers – Vision/hearing	Qualitative research suggests hearing impairment impedes information access (Eames et al., 2010)
Barriers – Memory	Qualitative research suggests poor recall impedes information access (Eames et al., 2010); stroke survivors with low HL had poorer education retention (Sanders et al., 2014)
Barriers - Motivation	Qualitative research suggests "never asking" impedes information access (Eames et al., 2010); Motivation is a key attribute for HL (Sorensen et al., 2012).
Barriers – time/demands	Qualitative research suggests ""not having time" –caregiver and participant and ""health getting in the way" impedes information access (Eames et al., 2010);

Variable	Rationale
Barriers – Transportation	Low health literacy associated with transportation needs for transitional care (Boyle et al., 2017)
Barriers – HCP relationship	Qualitative research suggests "limited access to staff" "feeling intimidated" "poor communication with staff" impedes information access (Eames et al., 2010; Roy et al., 2015)
Barriers – care continuity	Qualitative research suggests "Disruption in the continuity of care" impedes information access (Eames et al., 2010)
Barriers – Physical environment	Qualitative research suggests hospital environment is a barrier to accessing information post stroke (Eames et al., 2010)
Barriers – information delivery	Qualitative research suggests limited availability, suitability, medical jargon, lack of written is a barrier to accessing information post stroke (Eames et al., 2010). Interactive video medium preferred in one study (Aran et al., 2022). Qualitative data suggests timing of information delivery may be important (Roy et al., 2015). Qualitative research suggests "feeling overwhelmed" impedes information access (Eames et al., 2010); Information delivery can impact ability to engage HL skills in IMoHL (Sorensen et al., 2012).
Barriers – uncomfortable (stigma)	Feeling uncomfortable asking doctors and nurses to explain information was used in a prior study to measure stigma and found to be significantly associated with low health literacy (Ussher et al., 2010)
Barriers - Technology	Qualitative research suggests ""Being in hospital all the time [with] no access to internet with printer" impedes information access (Eames et al., 2010)
Self efficacy (preparedness)	Higher health literacy associated with higher Medication understanding and use self-efficacy (MUSE) (Appalasamy et al., 2019)
Read stroke binder/SPC info package	Utility of existing resources
Perception of stroke recovery	Functional impact of the stroke can impair access to information (Eames et al., 2010)
Health information needs met	In prior studies MIS survivors report un met health information needs (Crow, 2018; Green &King, 2007; Edwards et al., 2006)

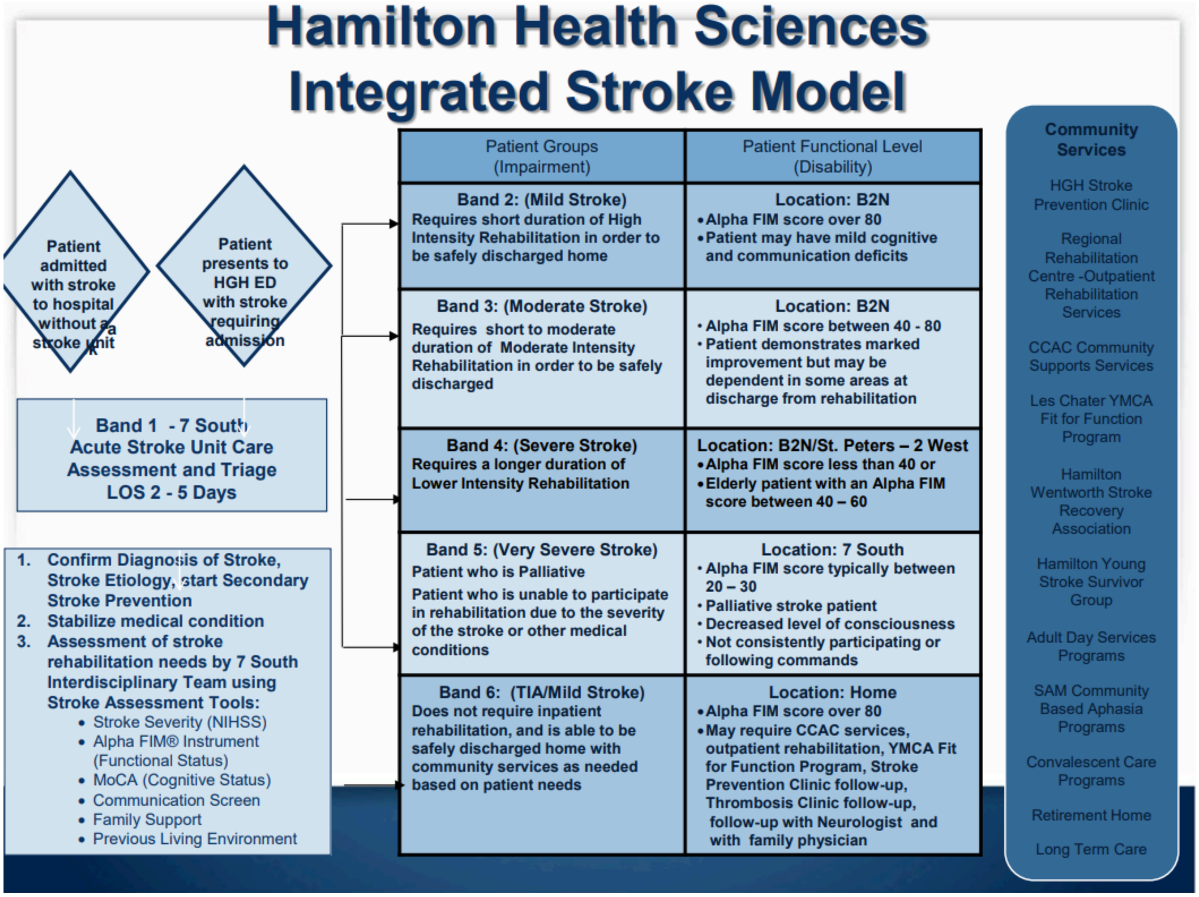
Appendix H:

Classification of barriers from the question “Did any of the following factors make it more difficult to get, understand, judge or use health information related to your stroke” between the determinants defined in the integrated model of health literacy

Personal	Situational	System (societal)
Fatigue Language barrier Communication Difficulty Vision/Hearing difficulty Memory difficulty Decreased motivation Other medical issues	Physical environment How the information was delivered Timing of information delivery HCP trustworthiness Financial difficulties Access to technology	Transportation Continuity of care providers Access to care providers Complexity of healthcare system Time constraints/Competing demands Feeling uncomfortable (stigma) Limited health care resources

Appendix I

Hamilton Health Sciences Integrated Stroke Model (Hamilton Health Sciences, 2011)



Hamilton Health Sciences Integrated Stroke Model

Patient admitted with stroke to hospital without a stroke unit

Patient presents to HGH ED with stroke requiring admission

Band 1 - 7 South
Acute Stroke Unit Care
Assessment and Triage
LOS 2 - 5 Days

1. **Confirm Diagnosis of Stroke, Stroke Etiology, start Secondary Stroke Prevention**
2. **Stabilize medical condition**
3. **Assessment of stroke rehabilitation needs by 7 South Interdisciplinary Team using Stroke Assessment Tools:**
    - Stroke Severity (NIHSS)
    - Alpha FIM® Instrument (Functional Status)
    - MoCA (Cognitive Status)
    - Communication Screen
    - Family Support
    - Previous Living Environment

Patient Groups (Impairment)	Patient Functional Level (Disability)
Band 2: (Mild Stroke) **Requires short duration of High Intensity Rehabilitation in order to be safely discharged home**	**Location: B2N** • **Alpha FIM score over 80** • **Patient may have mild cognitive and communication deficits**
Band 3: (Moderate Stroke) **Requires short to moderate duration of Moderate Intensity Rehabilitation in order to be safely discharged**	**Location: B2N** • **Alpha FIM score between 40 - 80** • **Patient demonstrates marked improvement but may be dependent in some areas at discharge from rehabilitation**
Band 4: (Severe Stroke) **Requires a longer duration of Lower Intensity Rehabilitation**	**Location: B2N/St. Peters – 2 West** • **Alpha FIM score less than 40 or** • **Elderly patient with an Alpha FIM score between 40 – 60**
Band 5: (Very Severe Stroke) **Patient who is Palliative** **Patient who is unable to participate in rehabilitation due to the severity of the stroke or other medical conditions**	**Location: 7 South** • **Alpha FIM score typically between 20 – 30** • **Palliative stroke patient** • **Decreased level of consciousness** • **Not consistently participating or following commands**
Band 6: (TIA/Mild Stroke) **Does not require inpatient rehabilitation, and is able to be safely discharged home with community services as needed based on patient needs**	**Location: Home** • **Alpha FIM score over 80** • **May require CCAC services, outpatient rehabilitation, YMCA Fit for Function Program, Stroke Prevention Clinic follow-up, Thrombosis Clinic follow-up, follow-up with Neurologist and with family physician**

Community Services

HGH Stroke Prevention Clinic

Regional Rehabilitation Centre -Outpatient Rehabilitation Services

CCAC Community Supports Services

Les Chater YMCA Fit for Function Program

Hamilton Wentworth Stroke Recovery Association

Hamilton Young Stroke Survivor Group

Adult Day Services Programs

SAM Community Based Aphasia Programs

Convalescent Care Programs

Retirement Home

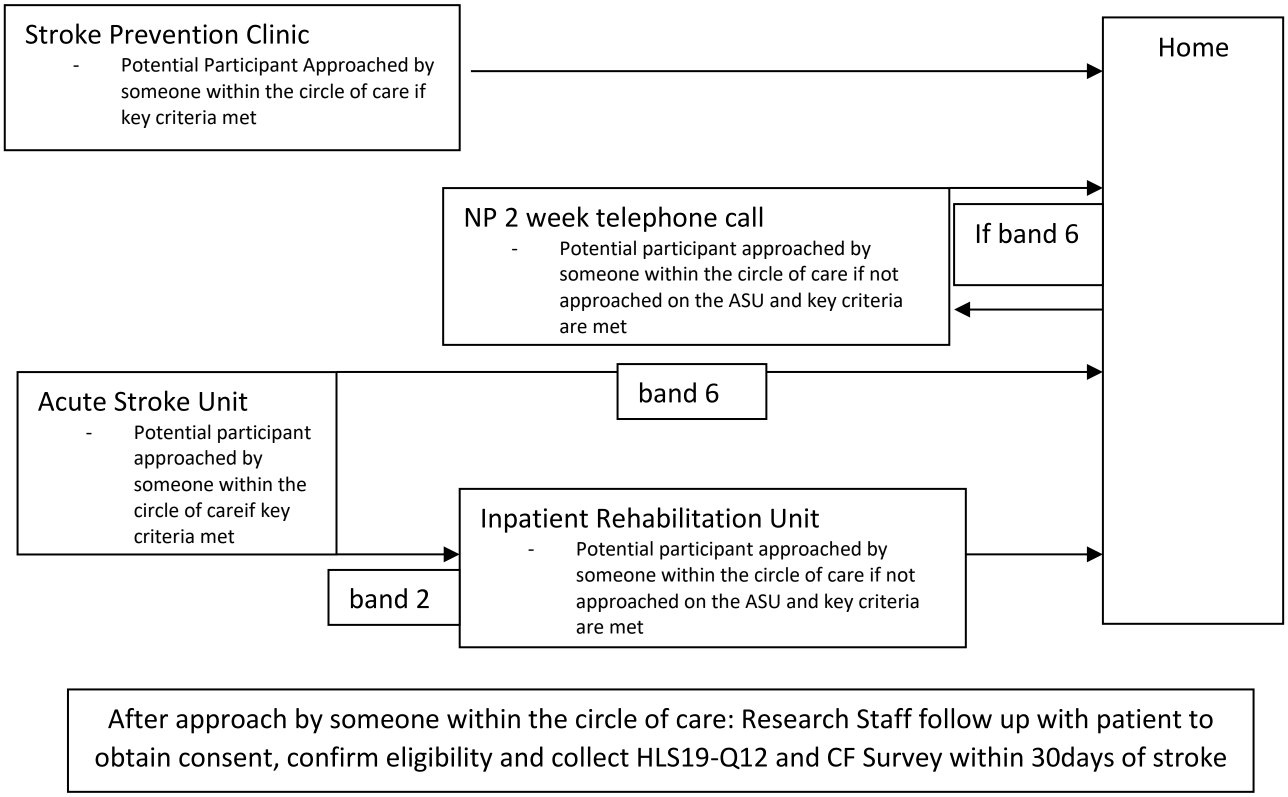
Long Term Care

Appendix J

Recruitment Diagram

Key criteria for clinician pre-screening:

- Recent (≤30 days) ischemic stroke (diagnosed by a physician specializing in stroke or confirmed by CT or MRI)
- Mild deficits (NIHSS ≤ 5 or recruited from stroke prevention clinic)
- Ability to provide informed consent



Stroke Prevention Clinic
- Potential Participant Approached by someone within the circle of care if key criteria met

NP 2 week telephone call
- Potential participant approached by someone within the circle of care if not approached on the ASU and key criteria are met

Acute Stroke Unit
- Potential participant approached by someone within the circle of careif key criteria met

Inpatient Rehabilitation Unit
- Potential participant approached by someone within the circle of care if not approached on the ASU and key criteria are met

After approach by someone within the circle of care: Research Staff follow up with patient to obtain consent, confirm eligibility and collect HLS19-Q12 and CF Survey within 30days of stroke

Appendix K

LETTER OF INFORMATION / CONSENT

Study Title: Determining the level of health literacy and EXPLORring contExtual factors associated with Health Literacy in recent minor ischemic stroke survivors returning to the community within 30 days post stroke (EXPLORE HL)

Investigators:

Local Principal Investigator:
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Department of Nursing
McMaster University
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(905) 525-9140 ext. 21435
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Student Investigator:
Cheyanne Vandervelde
Department of Nursing
McMaster University
Hamilton, ON, Canada
Phone: 905-973-1298
E-mail: vanderck@mcmaster.ca

Purpose of the Study

You are invited to take part in this research study about health literacy because you have had a minor ischemic stroke.

Health literacy refers to a person's ability to get, understand, judge and use health information to make decisions in everyday life. It is not always easy to get understandable, reliable and useful information about health. Difficulty with health literacy has been linked with poor health outcomes after illness. A person's health literacy is shaped by personal and environmental factors around them. These factors are referred to as contextual factors.

An ischemic stroke occurs when a blood vessel in the brain is blocked and causes injury to the brain. A stroke is considered minor if the person is able to go home shortly after their stroke. People with minor ischemic stroke use information to attend appointments, take medication, identify new symptoms, know when to get help, and decide when to resume pre-stroke activities or if changes are needed.

This study is being completed as a master's thesis in the School of Nursing. We hope to find out how easy or difficult it is for stroke survivors like you to perform tasks related to getting and using health information. We also hope to find out whether this is different from the general population and factors that may be associated with it.

What will happen during the study?

This study will include 42 participants. You are eligible for this study because you are within 30 days of your stroke. You will be asked to sign this form or provide your verbal consent to participate in the study.

You will be asked to complete two surveys with the researcher:

1) The 12 question health literacy survey (HLS19-Q12). The researcher will ask you to rate how easy or hard it is to perform 12 tasks related to handling health information.
2) A contextual factors survey. The researcher will ask you about many factors related to handling health information.

Each survey will take about 5 minutes to complete. We are hopeful that you will provide a response to all questions. However, you may choose not to answer some or all questions.

We will also obtain more information from your medical record. This includes information about you, your stroke and use of health care services during the 30 days after your stroke.

Are there any risks to doing this study?

The risks involved in participating in this study are minimal. You may feel uncomfortable with answering some questions. Some questions may be difficult to understand. We encourage you to ask questions if you do not understand the question. You do not need to answer questions that you do not want to answer or that make you feel uncomfortable. You can stop to take a break. You can withdraw (stop taking part) in the study at any time. We describe below the steps we are taking to protect your privacy. By participating in this study you do not give up any rights to which you may be entitled under the law.

Are there any benefits to doing this study?

The research will not benefit you directly. We hope to learn more about how recent stroke survivors handle health information and the relationship with contextual factors. We hope that what is learned from this study will help us to better understand health literacy in recent stroke survivors. This could help the design of future research, programs or supports for recent stroke survivors.

Confidentiality

Every effort will be made to protect your confidentiality and privacy. All records identifying you will be kept confidential and, to the extent permitted by the applicable laws and/or regulations, will not be made publicly available. Identifiable information such as your name will not be recorded on the data collection sheets or within the database. You will be assigned a unique study number which will be recorded on data collection sheets and within the database. The study key linking the study number and you will remain separate from the database. At the end of the study the study key will be destroyed and the data will be anonymized.

The data you provide will be kept in a locked cabinet where only the research staff will have access to it. Information kept on a computer will be protected by a password. Once the study has been completed, the study key will be destroyed. An archive of the anonymized data, without identifying information, will be kept.

At the end of the study, your de-identified data may be deposited into one or more publicly-accessible scientific repositories, such as McMaster Dataverse, through which researchers from around the world will have access to these data for future research.

A member of the Hamilton Integrated Research Ethics Board, this institution or regulatory authorities, may consult your original (identifiable) research data and medical records. However, no records which identify you by name or initials will be allowed to leave the hospital. By participating in this study, you authorize such access.

To assess whether you are eligible for the study, some screening data about you is collected. If you are not eligible for the study this data will be deleted.

What if I change my mind about being in the study?

Your participation in this study is voluntary. It is your choice to be part of the study or not. If you decide to be part of the study, you can decide to stop (withdraw), at any time, even after signing the consent form or part-way through the study. If you choose to withdrawal from the study, please contact the student investigator or the Local Principal Investigator on the first page of this document. Information provided up to the point where you withdraw will be kept unless you request that it be removed. If you do not want to answer some of the questions you do not have to, but you can still be in the study. Your decision whether or not to be part of the study will not affect your continuing access to services.

How do I find out what was learned in this study?

We expect to have this study completed by approximately December 2023. If you would like a summary of the results, please let me know how you would like it sent to you.

Questions about the Study

If you have questions or need more information about the study itself, please contact the student investigator at vanderck@mcmaster.ca or 905-973-1298.

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HiREB). The HiREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the Chair, HiREB, at 905.521.2100 x 42013.

CONSENT STATEMENT

☐**Verbal Consent:**

This section will be completed if the participant is providing verbal informed consent

The participant has read the consent form, had an opportunity to ask questions and those questions have been answered. The participant verbally agreed to participation in the study. The participant will receive a copy of the informed consent form including this completed signature page.

PRINTED NAME of Participant	Date consent was provided

PRINTED NAME & ROLE	Signature of Person Conducting the Consent Discussion	Date

Witness:(required if participants are unable to read in English)
I was present when the information in this form was explained and discussed with the participant. I believe the participant understands what is involved in this study.

Name	Signature	Date

☐**Written Consent**

This section will be completed if the participant is providing written informed consent

I have read the preceding information thoroughly. I have had an opportunity to ask questions and all of my questions have been answered to my satisfaction. I agree to participation in the study. I understand that I will receive a signed copy of this form.

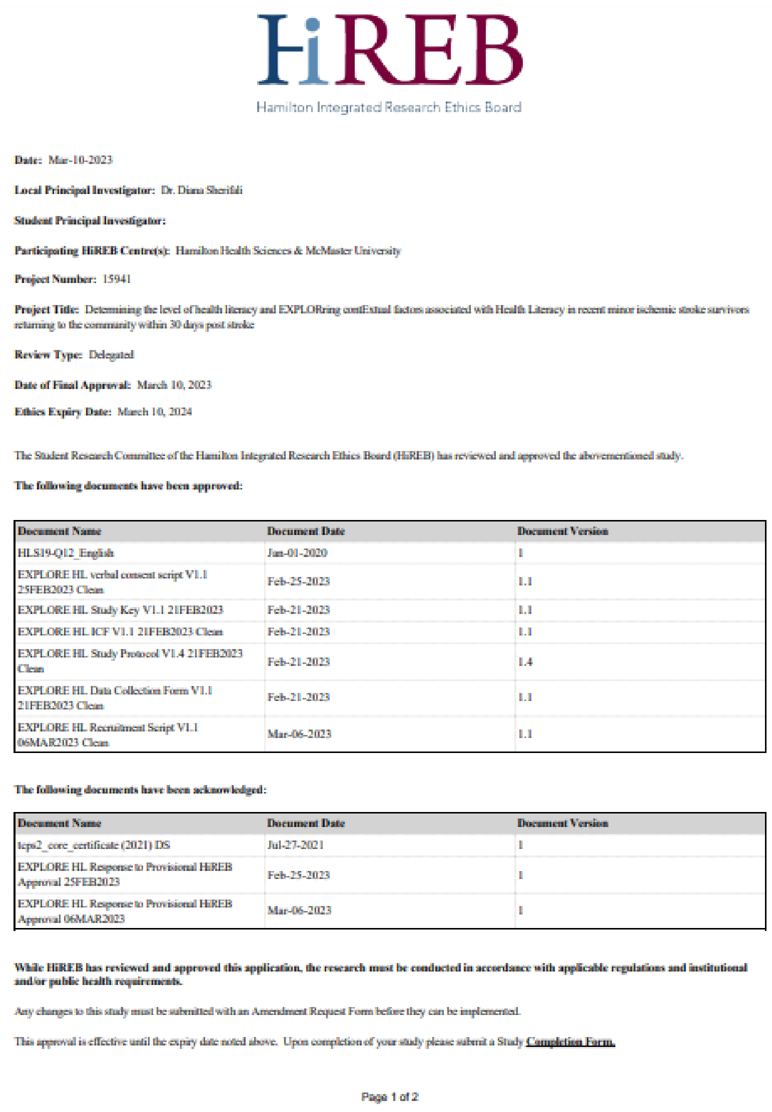
PRINTED NAME of Participant	Signature	Date

PRINTED NAME & ROLE	Signature of Person Conducting the Consent Discussion	Date

Witness:(required if participants are unable to read in English)
I was present when the information in this form was explained and discussed with the participant. I believe the participant understands what is involved in this study.

Name	Signature	Date

Appendix L



HiREB

Hamilton Integrated Research Ethics Board

Date: Mar-10-2023

Local Principal Investigator: Dr. Diana Sherifali

Student Principal Investigator:

Participating HiREB Centre(s): Hamilton Health Sciences & McMaster University

Project Number: 15941

Project Title: Determining the level of health literacy and EXPLORring contExtual factors associated with Health Literacy in recent minor ischemic stroke survivors returning to the community within 30 days post stroke

Review Type: Delegated

Date of Final Approval: March 10, 2023

Ethics Expiry Date: March 10, 2024

The Student Research Committee of the Hamilton Integrated Research Ethics Board (HiREB) has reviewed and approved the abovementioned study.

The following documents have been approved:

Document Name	Document Date	Document Version
HLS19-Q12_English	Jan-01-2020	1
EXPLORE HL verbal consent script V1.1 25FEB2023 Clean	Feb-25-2023	1.1
EXPLORE HL Study Key V1.1 21FEB2023	Feb-21-2023	1.1
EXPLORE HL ICF V1.1 21FEB2023 Clean	Feb-21-2023	1.1
EXPLORE HL Study Protocol V1.4 21FEB2023 Clean	Feb-21-2023	1.4
EXPLORE HL Data Collection Form V1.1 21FEB2023 Clean	Feb-21-2023	1.1
EXPLORE HL Recruitment Script V1.1 06MAR2023 Clean	Mar-06-2023	1.1

The following documents have been acknowledged:

Document Name	Document Date	Document Version
tcps2_core_certificate (2021) DS	Jul-27-2021	1
EXPLORE HL Response to Provisional HiREB Approval 25FEB2023	Feb-25-2023	1
EXPLORE HL Response to Provisional HiREB Approval 06MAR2023	Mar-06-2023	1

While HiREB has reviewed and approved this application, the research must be conducted in accordance with applicable regulations and institutional and/or public health requirements.

Any changes to this study must be submitted with an Amendment Request Form before they can be implemented.

This approval is effective until the expiry date noted above. Upon completion of your study please submit a Study **Completion Form.**

Page 1 of 2

If you require more time to complete your study, you must request an extension in writing before this approval expires. Please submit an **Annual Review Form** with your request.

PLEASE QUOTE THE ABOVE REFERENCED PROJECT NUMBER ON ALL FUTURE CORRESPONDENCE

REB members involved in the research project do not participate in the review, discussion or decision.

The Hamilton Integrated Research Ethics Board (HiREB) provides ethical review and ongoing ethical oversight on behalf of Hamilton Health Sciences, St. Joseph's Healthcare Hamilton, Research St. Joseph's-Hamilton, the Faculty of Health Sciences at McMaster University and Niagara Health. HiREB operates in compliance with and is constituted in accordance with the requirements of: The Tri-Council Policy Statement on Ethical Conduct of Research Involving Humans (TCPS 2); The International Conference on Harmonisation of Good Clinical Practices Guideline (ICH GCP); Part C Division 5 of the Food and Drug Regulations, Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act 2004 and its applicable Regulations. For studies conducted at St. Joseph's Healthcare Hamilton, HiREB complies with the Health Ethics Guide of the Catholic Alliance of Canada. HiREB is qualified through the Clinical Trials Ontario (CTO) REB Qualification Program and is registered with the U.S. Department of Health and Human Services (DHHS) Office for Human Research Protection (OHRP).

Good luck with your research,

Kristina Trim, PhD, RSW
Chair, HiREB Student Research Committee
McMaster University

Page 2 of 2