

THE IMPORTANCE OF INCORPORATING STROKE SURVIVORS' HEALTH PERCEPTIONS IN ADDRESSING HEALTH CARE DISPARITIES

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Patient-centered research in determining health care disparities among stroke patients is limited. Several studies have examined patient perceptions in stroke survivors and have utilized the Illness Perceptions Questionnaire-Revised (IPQ-R) and Brief Illness Perceptions Questionnaire (BIPQ), which are validated measures of illness beliefs. Yet, there are several domains these surveys could assess that warrant more investigation, including: perception of medication side effects; acceptance of the stroke diagnosis; consequence and long-term impact of symptoms; the importance of medications in long-term health maintenance; and perception of ease of access to equitable health care. Though these surveys are available, representation of diverse and under-represented groups within stroke surveys utilizing them is low. Also, only a limited number of studies of stroke patients' perceptions have focused on health disparities or specifically beliefs and attitudes of under-represented stroke survivors. Due to insufficient current research, future studies should focus on using these patient perception questionnaires with underrepresented populations. Improvements in this field may allow providers to offer patient-centered care among a diverse population, bridging gaps in health care equity. *Ethn Dis.* 2022;32(2):145-148; doi:10.18865/ed.32.2.145

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INTRODUCTION

Recently, researchers have been exploring methods to close health disparities in stroke. We argue that incorporating stroke patients' beliefs into standard post-stroke care can help bridge gaps in health care equity by improving patient-provider communication to increase the likelihood that patients' needs are being met. Consequently, improved equity via improved care coordination practices can improve outcomes, which can help lead to reduced long-term disability and costs associated with stroke in these vulnerable populations. In this commentary, we offer evidence that the use of health perception questionnaires, grounded in theoretical models, such as the Health Belief Model (HBM)¹ and the Common-Sense Model,² can be utilized to evaluate a patient's perception of the seriousness of their condition and their susceptibility to illness. In addition, providers can use that information to improve stroke outcomes. More importantly, combining concepts from the HBM can enhance the specificity of the health percep-

tion questionnaires and obtain a more comprehensive assessment of belief patterns.¹ Providers can then translate this enhanced assessment into achieving better stroke-related outcomes.

This commentary argues for a more significant consideration of health care perceptions held by stroke patients in order to more effectively deliver health care to these patients. This is especially important in minority populations where research is currently limited and a higher incidence of stroke and cerebrovascular disease has been found in the Black, Hispanic, American Indian, or Alaska Native population.³⁻⁵ By understanding patients' beliefs and attitudes, providers can bridge gaps in health care equity and preventative care in stroke patients to improve the quality of stroke care, especially at discharge.^{6,7} We define health care perceptions as multifactorial, including patients' beliefs and feelings regarding their illness, attitudes toward their medications, and willingness and hesitation to utilize the health care system.

Patients' perceptions of health and treatment goals are essential for patient-centered care. We know stroke patients' attitude toward their illness is predictive of how likely they are to engage with the health care system and adhere to recommended treatment plans.⁸ Patients who

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perceive their post-stroke life as non-modifiable may perceive stroke recovery as impossible, have difficulty with medication adherence, or be unable to make needed long-standing lifestyle changes.⁸ This is particularly important for stroke management since approximately 87% of stroke risk is modifiable with aggressive management of stroke risk factors such as hypertension, diabetes, and obesity.^{3,9} Also, it is estimated that 47% of strokes are due to behavioral risk factors such as smoking, diet, and sedentary lifestyle. Notably, these preventable risk factors often require coordinated care and management between patients and health care providers. Thus, any barriers to an effective patient-provider relationship can decrease the potential for optimal stroke prevention or sustained engagement in therapies needed for stroke recovery.

METHODS

We used a systematic approach to identify current literature regarding patient perceptions, illness beliefs, secondary stroke prevention, risk factor management, and racial and ethnic disparities. We searched the following databases: MEDLINE, WorldCat, PubMed, George Smathers Library, and Google Scholar using the following search criteria: (“illness perception” OR “illness belief”) AND (“stroke” OR “TIA” OR “transient ischemic attack” OR “cerebrovascular event” OR “cerebrovascular accident” OR “CVA”). Systematic reviews and meta-analyses were excluded. An initial review found that the majority of studies did not have significant representation from under-represented groups, and a limited number

of studies identified disparities or suggested methods to reduce them. Thus, 21 out of 452 articles were selected for data analysis; findings from these articles are explored in this commentary.

COMMENTARY ON FINDINGS

As found by Cruz-Flores et al, the perception of racial bias may play a role in compliance.¹⁰ Knowledge of stroke symptoms plays a role in secondary prevention. Symptom awareness, especially prominent in women, can be persistently lacking post-stroke.¹⁰ Other researchers have proposed that identifying patient post-stroke behaviors can teach health professionals to effectively communicate risk factors to stroke survivors and the general population.¹¹ Yet, the long-term effects of education are unknown.

Research also suggests that racial disparities exist in acute treatments for stroke.^{10,12} Non-White stroke patients experience disparities in stroke care and outcomes.¹³ Access to care is a suggested explanation for these disparities.¹⁴ In South Carolina, ethnic disparities were evaluated within their telestroke network where the researchers found that more non-White patients, the majority being African American, were seen at a primary stroke center.¹² Yet, White patients were more likely to receive tPA (OR, 1.47; 95%CI, 1.17 – 1.84) and received it within the recommended time frame, DRN \leq 45 minutes (OR 1.76, 95%CI 1.31 – 2.66), even after adjusting for co-morbidities.¹² Evidence such as this is currently limited, and further research is necessary.

The patient interview is the most common way providers assess patient

attitudes and beliefs,¹⁵ but informal assessments may miss pertinent information. Alternatively, patient perception questionnaires can be used adjunctively with routine care or clinical research outcomes data. Three forms of health perceptions questionnaires have been validated for use in stroke populations, including two Illness Perceptions Questionnaires (IPQ)¹⁶ and the Health Belief Model (HBM).^{1,17} These survey instruments have been used in multiple countries including, Brazil, China, Greece, Sweden, Scotland, the United Kingdom, and the United States. The two IPQs, which differ in length, assess patients' perceptions of their illness by evaluating their interpretation of the significance of the disease, the cause and consequence of the disease, and understanding the interventions needed to maintain or improve their health condition.¹⁷ The IPQ-revised (IPQ-R) is longer, while the Brief Illness Perceptions Questionnaire (BIPQ) is shorter, including 10 questions. The IPQ-R has good test-retest reliability in stroke survivors.¹⁷ In contrast, the BIPQ has the benefit of brevity and good test-retest reliability.⁸ The IPQ, in particular, can help identify vulnerable stroke patients who are suffering psychosocial stress due to their stroke.⁸

Stroke survivors who do not have an optimistic outlook on the potential for health improvement may have more anxiety, depression, and report an increase in distress in the months after a stroke.¹⁸ Strong beliefs about the cause of stroke, adverse sequela resulting from the stroke, and lower patient coherence were associated with significant distress in patients and their caregivers.¹⁸ Patients were also more likely to believe that psychological factors

such as life stressors were the cause of the stroke if they expressed high indicators of distress on the IPQ.¹⁸ Moreover, the IPQ shows that non-adherent stroke survivors were more likely to believe that they would not return to their pre-stroke functional status.⁸

While IPQs assess psychosocial domains, the HBM survey evaluates patients' perceptions of treatment modalities, the likelihood a patient will actively engage in the health plan, and patient/caregiver distress.^{8,18} The HBM survey seeks to understand patients' perception of susceptibility to illness, the seriousness of the condition, the benefits of actively engaging in health care, and identify barriers that may prevent a patient from changing behavior to improve health.¹ Also, the HBM assesses the influence of patients' impressions of the long-term implications of their stroke and their risk of stroke re-occurrence.^{1,18} Combining the HBM and IPQs can enhance the specificity of the questionnaires.

An essential component of behavior change is perceived risk.¹⁹ Behavior change research suggests that accurate assessment and incorporation of perception of risk leads to compliance with prevention methods.¹⁹ The SWIFT study included an ethnically diverse cohort of stroke survivors.²⁰ This study investigated the baseline relationship of risk perception, health beliefs, and demographics; no significant differences were found regarding accurate risk estimation for race-ethnicity.²⁰ Of the 817 participants, 20% accurately estimated their recurrent risk of stroke, 10% underestimated risk, and 70% significantly overestimated their risk.²⁰ History or knowledge of cerebrovascular accident (CVA) risk factors were

not associated with the inaccurate risk estimation.²⁰ Yet, worry, fatalism, and memory problems were associated with inaccurate risk estimation.²⁰ Accurate risk perception can help stroke survivors adopt healthy behaviors to reduce recurrence risk. Emotional lability and thus risk perception can be identified via the IPQ surveys, which can identify vulnerable populations that can be helped via additional interventions.

The IPQ surveys have primarily been administered to White, non-Hispanic populations, which reduces the generalizability of the results. Nevertheless, it illustrates the need for future studies to administer these surveys to minority populations. When minorities have been the target population, depression and medication adherence have been co-variables of interest. When the IPQ-R was administered in the Atlanta metro area, a predominately African American population, stroke survivors had difficulty identifying their symptoms and focused on their fatigue and frustration.²¹ Phillips et al conducted a study in underserved communities in New York City and found that illness and treatment beliefs were positively related to medication adherence.²²

On the other hand, there are limitations to these surveys. Questionnaires may be challenging for patients with cognitive impairment and aphasia post-stroke.^{23,24} Newington & Metcalfe have suggested that common post-stroke impairments (ie, paralysis and perceptual difficulties) undeniably make informed consent and participation difficult for acute stroke research.²³ They theorized that reducing participant burden can improve the recruitment of this population.²³ Various methods that can reduce this burden include administering

the survey verbally, which also combats reading comprehension difficulty.²⁵ To reduce fatigue, which is especially common in stroke survivors, the survey length can be reduced, and negatively worded items can be removed.²⁵ Negatively worded items have affected some of the IPQ sub-scales in previous studies.²⁵ Future studies should consider removing them as the benefit of reducing complexity may outweigh the potential of response bias.²⁵

CONCLUSION

Using patient perception questionnaires can aid in identifying vulnerable patients. Emotional variability, misunderstanding of future risk, limited belief in treatment potential, post-stroke associated stress, and caregiver distress have been associated with medication non-compliance and less compliance with healthy behavior change.^{8,18,22} Identifying these negative beliefs is the first step toward better stroke outcomes. Improving health behaviors via improving patients' health beliefs has improved blood pressure control, medication adherence, and reduced disability in stroke survivors.^{26,27} These questionnaires can provide a method for obtaining a more comprehensive assessment of belief patterns that can significantly affect stroke outcomes. Due to limited current research, future studies should focus on using these patient perception questionnaires on underserved and disadvantaged populations. Improvements in this field may allow providers to offer patient-centered care among a diverse population, bridging gaps in health care equity.

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CONFLICT OF INTEREST

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AUTHOR CONTRIBUTIONS

Research concept and design: Dickens, Gyang, Sanders; Acquisition of data: Dickens; Data analysis and interpretation: Dickens, Gyang; Manuscript draft: Dickens, Gyang, Sanders, Ellis, Simpkins; Acquisition of funding: Dickens; Administrative: Sanders; Supervision: Gyang, Simpkins

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