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Language, Literacy, and Characterization of Stroke Among Patients Taking Warfarin for Stroke Prevention: Implications for Health Communication

Margaret C. Fang¹, Praveen Panguluri², Edward L. Machtinger³, and Dean Schillinger⁴

¹ Division of Hospital Medicine, University of California, San Francisco (San Francisco, CA)

² University of California, San Francisco School of Medicine (San Francisco, CA)

³ University of California, San Francisco Department of Medicine (San Francisco, CA)

⁴ University of California, San Francisco Department of Medicine, Center for Vulnerable Populations (San Francisco, CA)

Abstract

Objective—Warfarin is a medication commonly prescribed to prevent strokes associated with certain medical conditions such as atrial fibrillation; however, little is known about how people taking warfarin perceive the goal of therapy and how they describe strokes. We assessed the stroke-related health literacy of anticoagulated patients to inform ways in which to improve health communication among people taking warfarin.

Methods—We conducted a mixed-methods study of an ethnically and linguistically diverse sample of people taking warfarin to prevent stroke (N=183) and measured literacy using the short-form Test of Functional Health Literacy in Adults. We asked participants to (1) describe their indication for warfarin, and (2) describe a stroke. Transcribed answers were coded as *concordant* or *discordant* with established indications for warfarin and definitions of stroke.

Results—Forty-three percent of participants provided a discordant response when describing their indication for warfarin. Only 9.3% reported that the purpose of taking warfarin was to prevent stroke. Not speaking English [OR = 2.4 (1.1–5.6)] and less than a college education [OR = 3.3 (1.4–7.3)] were independently associated with discordant answers about warfarin. Nearly 40% of subjects had inaccurate perceptions of stroke, and only one-third of subjects described a symptom or sign of stroke. Among English and Spanish-speaking participants, inadequate literacy was strongly associated with discordant responses about stroke [OR = 5.8 (2.1–15.6)].

Conclusion—Among high risk people taking warfarin to prevent stroke, significant gaps in stroke-related health literacy exist. These gaps likely represent mismatches in the ways clinicians teach and patients learn.

Corresponding Author: Margaret C. Fang, 503 Parnassus Ave., Box 0131, San Francisco, CA 94143, Phone: (415) 502-7100, Fax: (415) 514-2094, Email: mfang@medicine.ucsf.edu.

Disclosures

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Practice implications—Since stroke risk awareness and early recognition of the signs and symptoms of stroke are critical aspects of stroke prevention and treatment, clinicians should more strongly link warfarin therapy to stroke prevention and ensure that patients know the presenting symptoms and signs of stroke. Public health communication strategies regarding stroke prevention need to target individuals with limited literacy and limited English proficiency.

Keywords

health literacy; language barriers; disparities; anticoagulation; knowledge; stroke; communication

1. Introduction

Stroke is the third leading cause of death and a major contributor to disability in the United States(1). Although there have been widespread efforts to improve the public's recognition of the risk factors and symptoms of stroke, the awareness of stroke (stroke-related health literacy) remains far from optimal(2),(3). The principal reasons to promote general awareness of stroke include (1) increasing motivation and uptake of proven preventive therapies (such as antihypertensive or anticoagulant treatment) so as to reduce the population burden of stroke, and (2) increasing rates of early stroke symptom recognition so as to increase access to time-sensitive therapies, including intravenous thrombolytics or early evaluation in special stroke centers(4).

Several medical conditions, such as atrial fibrillation or having a prosthetic heart valve, significantly raise the risk of ischemic stroke(5). Atrial fibrillation is a particularly important risk factor for stroke, affecting over 2.3 million people in the United States and causing approximately 15% of all strokes(6). Without treatment, the annual incidence of stroke in people with atrial fibrillation can range between 1% and 12%(5). For people with risk factors for stroke such as atrial fibrillation, promoting a high level of awareness of available preventive therapies and teaching people how to recognize and seek treatment for the symptoms of stroke represent a particularly compelling health communication imperative.

In people who have atrial fibrillation, prior stroke, or prosthetic heart valves, chronic anticoagulation treatment with warfarin sodium is frequently indicated to reduce the risk of ischemic stroke(5). However, warfarin is a notoriously complex therapy that raises bleeding risk and places significant demands on patients in terms of frequent monitoring and adherence to therapy(7). Prior research has shown that limited literacy and numeracy are strongly associated with deficiencies in warfarin-related knowledge(8). Ideally, in considering this stroke prevention therapy, patients engage in a shared decision-making process that helps them weigh the potential benefit of stroke-related risk reduction against the potential harm of increased bleeding. Once patients have decided to undergo chronic anticoagulation, they need to be aware that they remain at risk for stroke and that optimal and safe management of warfarin requires close monitoring(7).

While prior literature has emphasized the importance of educating people about warfarin management and side-effects(8,9), little is known about how people who take warfarin perceive the benefits of therapy and, specifically, the degree to which they identify stroke prevention as the primary rationale for therapy. People unfamiliar with stroke or stroke symptoms may be less likely to perceive themselves at risk and/or seek prompt treatment (10–13).

Increasing our understanding of the stroke-related health literacy of populations at risk for stroke could have important implications for creating more robust health communication interventions at both the public health and health service levels. Hence, this mixed-methods study was conducted to assess stroke-related health literacy among diverse patients who are at

high risk for stroke and who are receiving chronic warfarin to prevent stroke. In attempting to operationalize the concept of stroke-related health literacy for this particular sample of patients, we were particularly interested in examining both whether prevention of stroke is a central theme in how people taking warfarin perceive the purpose of warfarin therapy, as well as whether they describe stroke in ways that would lead to patterns of sustained preventive therapy and early recognition of stroke. Given the disproportionate burden of limited literacy among the elderly, people with cardiovascular diseases, and racial and ethnic minorities(14), as well as our own prior research regarding literacy and knowledge of warfarin management(8), we also measured the independent effects of patient literacy on stroke-related health literacy.

2. Methods

We enrolled consecutive, eligible patients seen from March 2002 to June 2003 at an anticoagulation clinic affiliated with a large, urban, public hospital in the San Francisco Bay Area. The clinic manages approximately 400 ethnically diverse and generally low income patients who take warfarin. Staff pharmacists provide patients individualized verbal education regarding the risks and side effects of warfarin beyond that already provided by referring physicians. Professional interpreters are also available to facilitate patient education. In addition, patients are given a one-page informational brochure written in their primary language (English, Spanish, Chinese, or Russian) and at an 8th grade reading level(15).

The details of the study procedures have been described in detail in a related manuscript(8). Briefly, patients were eligible if they were aged 18 years or older, spoke English, Chinese (Cantonese or Mandarin), or Spanish fluently, and were continually taking warfarin for at least 3 months to prevent stroke. We considered patients to be taking warfarin to prevent stroke if their indication for warfarin was atrial fibrillation, prosthetic heart valve, and/or prior stroke, as determined by review of the medical chart. Patients were excluded from the study if they were too ill to participate, had poor corrected visual acuity, or had a psychotic disorder, diagnosed dementia, or severe aphasia. Informed consent was obtained from all subjects prior to enrollment. The study was approved by the Institutional Review Board of the University of California, San Francisco.

Trained bilingual research assistants fluent in English and Spanish or Chinese verbally administered surveys and collected information on subject characteristics, including race/ethnicity, primary language, and educational attainment. Because both literacy and recall may be affected by undiagnosed cognitive deficits, we also administered the short-form of the Cognitive Abilities Screening Instrument (s-CASI), which has been validated in international dementia studies, does not require literacy, and has been shown to accurately measure cognition cross-culturally(16). We categorized significant cognitive impairment as a score < 17 on the s-CASI, as in prior studies(16).

For the subgroup of subjects who spoke English or Spanish, research assistants also measured literacy in the health care context using the short-form of the Test of Functional Health Literacy in Adults (s-TOFHLA), a 36-item timed reading comprehension test that has been validated in these two languages(17). Scores between 0 to 16 on the s-TOFHLA correspond to inadequate literacy, scores of 17 to 22 to marginal literacy, and scores of 23 or above, adequate literacy.

2.1. Outcomes

To assess stroke-related health literacy, research assistants asked subjects to respond to two open-ended questions in their own words: (1) "Can you tell me why are you taking warfarin/CoumadinTM?" and (2) "Can you describe what is a stroke?". The research assistants were instructed to prompt subjects to answer as completely as possible and to provide as much time as the subject needed. Research assistants then transcribed, and translated if needed, subject

responses verbatim. A research committee of three physicians then reviewed all transcribed responses, and through a consensus process, developed a coding scheme whereby responses to each item could reliably be categorized into distinct thematic domains (Figure 1 and Figure 2). Responses to each item were first coded as falling into the categories of *discordant* or *concordant* with established, widely accepted indications for warfarin, for example, “atrial fibrillation”, “blood thinner”, or “to prevent blood clots”, or *discordant* or *concordant* with widely accepted definitions for stroke, for example, “it affects the arteries leading to and within the brain”, “when a blood vessel that carries oxygen and nutrients to the brain is either blocked by a clot or bursts”, or “can cause paralysis ... speech/language problems ... vision problems”) (7,18,19). *Discordant* responses were then sub-categorized into those in which the subject reported “I don’t know” or those that reflected unconventional or vaguely worded indications for warfarin (Figure 1) or definitions of stroke (Figure 2). *Concordant* responses were sub-categorized into a discrete set of domains that emerged specific to established indications for warfarin or definitions of stroke (7,18,19). Once these coding categories and domains were developed, two study investigators blinded to subjects’ language and literacy level and indication for warfarin then individually coded each response into corresponding specific domains. Of note, individual responses could contain content that would generate coding into more than one distinct category. Discrepancies in coding between reviewers were uncommon and were resolved by consensus process, with a third investigator adjudicating if there was a continued difference in opinion.

2.2. Statistical analysis

We first described the proportion of subjects whose answers were discordant or concordant from standard indications for warfarin and definitions of stroke, and also described the proportion of answers that fell into the range of concordant domains. For each question, we then conducted bivariate comparisons of the association between subject characteristics and the proportion of subjects with discordant and concordant responses, using chi-squared tests to compare categorical variables and t-tests to compare continuous variables. Multivariable logistic regression was then used to test the independent association between patient characteristics and the likelihood of responding in specific domains. All variables tested in bivariate analyses were included in the multivariable model except for race/ethnicity, which was collinear with language ($r=0.64$). Finally, we conducted a subgroup analysis among English and Spanish speaking subjects, testing whether literacy level was associated with the likelihood of answering within specific domains, adjusting for other subject characteristics (specifically age, sex, years on warfarin, educational attainment, whether primary language was English, and s-CASI score). The multivariable models that assessed literacy did not include the variable for educational attainment, because of a moderate degree of collinearity with s-TOFHLA score ($r=0.58$)(20). All analyses were performed using SAS software 9.1 (SAS Institute, Cary, NC).

3. Results

We surveyed 183 people taking warfarin to prevent stroke. Subjects were of diverse racial/ethnic backgrounds and most had been taking warfarin for several years, primarily to reduce the risk of stroke from atrial fibrillation (Table 1).

3.1. Subjective characterization of warfarin indication

We identified five categories of responses, some discordant with and others concordant with established indications for warfarin (Figure 1): (1) *Discordant—didn’t know*; (2) *Discordant—other belief*, in which subjects described an unconventional or vaguely worded indication for warfarin; (3) *Concordant—underlying medical problem*, which referred to the condition for which the warfarin was prescribed; (4) *Concordant—mechanism*, which referred to the

ways in which warfarin works, most commonly “blood thinning”; and (5) *Concordant—treatment goal*, which referred to the prevention of an adverse event, such as stroke or blood clot. Table 2 contains representative excerpts from subject responses in the different categories.

Forty-three percent of participants provided a discordant response when describing their indication for warfarin (Table 3). One-third of all subject responses were categorized as “discordant—other belief”; of these, 50.8% stated that they took warfarin because their “blood was too thick” and 23.0% said they took warfarin because of “blood problems”. Within concordant domains, a little over one half described the underlying heart problem for which they took warfarin. Relatively few (25.1%) described the goal of warfarin, and only 9.3% specifically mentioned stroke prevention as a goal of therapy. Few subject responses involved two concordant domains and very few involved all three concordant domains.

In bivariate analysis, factors associated with discordant answers regarding warfarin therapy (i.e., replying “don’t know” or having an “other belief”) were older age (mean age 64.6 vs. 58.8 years, $p<0.01$), race/ethnicity (55.1% of Asian-American/Pacific Islander, 44.9% of Latino, 20.0% of white, and 15.0% of African-American subjects, $p<0.01$), lower educational attainment (51.2% among those with less than a college education vs. 22.2% among college educated subjects, $p<0.01$), not speaking English (48.5% vs. 25.5%, $p<0.01$), s-CASI score < 17 (70.4% vs. 37.8%, $p<0.01$), and fewer years on warfarin (mean 3.1 vs. 4.9 years, $p<0.01$). After multivariable adjustment, older age, lower educational attainment, not speaking English, and taking warfarin for fewer years were independently associated with a higher likelihood of discordant answers (Table 5).

3.2. Subjective perceptions of stroke

We identified five categories into which subject responses regarding stroke could be grouped, some discordant with, and others concordant with established definitions (Figure 2): (1) *Discordant—didn’t know*; (2) *Discordant—other belief*, where subjects used an unconventional description of stroke; (3) *Concordant—reference to brain damage*; (4) *Concordant—symptoms*, where subjects described neurologic or physical sequelae of stroke; and (5) *Concordant—mechanism*, where subjects described mechanisms causing stroke, such as blocked blood vessels or blood clots. Table 2 provides representative excerpts of how subjects characterized stroke.

Forty percent of participants provided discordant responses when describing stroke, with nearly a quarter of participants stating “I don’t know” (Table 3). People with answers categorized as “discordant—other belief” often confused stroke with heart or blood problems. For example, some stated that a stroke was “a mild heart attack”, “when your heart stops”, or “when there are problems with your blood”. Within concordant domains, there was an even distribution of responses, with one-third of the sample describing either brain damage, the mechanism, or the symptoms of stroke. Of the 33.3% of subjects who described symptoms of stroke, there was considerable heterogeneity in describing symptoms, with the most common being motor deficits or paralysis, such as “my hand, my leg can’t move” or “unable to walk” and less frequently, speech impairment, numbness, dizziness, or headache. Few subjects described two or three concordant domains (27.9% and 3.3% respectively, Table 3).

In bivariate analysis, subjects with discordant responses were older (mean age 64.0 vs. 59.4 years, $p=0.02$), more likely to be an ethnic minority (61.2% of Latino, 35.9% of Asian-American/Pacific Islander, and 30.0% of African-American, vs. 26.7% of white subjects, $p=0.01$), have lower educational attainment (48.8% among those with less than a college education vs. 20.4% among college educated, $p<0.01$), not speak English (44.9% vs. 27.7%, $p=0.04$), and score < 17 on the s-CASI (74.1% vs. 34.6%, $p<0.01$). After multivariable

adjustment, lower educational attainment and a s-CASI score < 17 continued to be associated with discordant responses about stroke (Table 5).

3.3. Sub-group analysis of literacy among English and Spanish speaking subjects

The mean s-TOFHLA score for the 146 subjects for whom we had measures of literacy was 17, corresponding to marginal levels of literacy. Table 2 provides examples of responses stratified by literacy levels.

With respect to the item asking about the indication for warfarin, half of subjects with inadequate literacy levels provided a discordant answer (“don’t know” or “other belief”) compared to 27.8% of those with marginal literacy and 23.1% with adequate literacy ($p<0.01$, Table 4). Fewer subjects with inadequate literacy described the goal of warfarin therapy as for stroke prevention (6.6% of subjects compared to 16.67% with marginal literacy and 15.4% of those with adequate literacy, $p=0.21$). After multivariable adjustment, although there was a trend towards a greater likelihood of discordant answers with inadequate literacy, this association did not reach statistical significance (Table 5).

With the respect to the item about stroke, subjects with inadequate literacy were the most likely to have discordant responses, with 40.8% of those with inadequate literacy stating “I don’t know” compared to 5.8% with adequate literacy. They were also least likely to include in their answers a description of the brain or the mechanism of stroke (Table 4). Only 15.8% of subjects with inadequate literacy provided answers that involved two or more concordant categories compared to 22.2% with marginal literacy and 59.6% with adequate literacy ($p<0.01$). After multivariable adjustment, inadequate literacy was significantly associated with a higher likelihood of a discordant answer regarding stroke (Table 5).

4. Discussion and conclusions

4.1 Discussion

Our study demonstrates that among a sample of patients at high risk for stroke and receiving warfarin therapy to prevent stroke, significant gaps in stroke-related health literacy exist. Only 9.3% of subjects reported that the purpose of taking warfarin was to prevent stroke, only one-third described a symptom or sign of stroke, and nearly 40% of participants had inaccurate perceptions of stroke. An individual’s perception of their susceptibility to an adverse outcome can be influenced by how much they know or can recall about the outcome; thus, people unfamiliar with stroke or stroke symptoms may be less likely to perceive themselves at risk for stroke or recognize stroke symptoms if they occur(10–12). While the stroke-related health literacy of the overall sample was sub-optimal, individuals with less educational attainment consistently demonstrated the lowest levels of stroke-related health literacy. Limited English proficiency and low educational levels were independent risk factors for discordant answers about warfarin indication and lower literacy levels were significantly associated with discordant answers regarding stroke.

Relatively few people described their indication for warfarin from the perspective of risk reduction, and among this subgroup, only a small minority specifically mentioned stroke prevention. While none of the participants had diagnosed hypercoagulable conditions, many perceived needing to take warfarin because their “blood was too thick” or because their “blood was not good”. Such statements, in part, may reflect the ways in which individuals interpret well-intended explanations from clinicians about the mechanism of action of warfarin as a “blood thinner”. Clinicians, concerned about the safety profile of warfarin, may spend a disproportionate time and effort discussing the warfarin-related risks of bleeding and the need for close monitoring(21), perhaps at the expense of explaining stroke prevention as the rationale

for treatment and developing awareness of stroke symptoms. This suggests that clinicians could improve their counseling of patients by conducting (1) an assessment of patients' understanding of stroke, (2) providing tailored explanations about stroke and stroke symptoms, and (3) framing the subsequent discussions around stroke risk reduction and early recognition of stroke symptoms.

4.2 Conclusion

Understanding the physical manifestations of stroke are necessary for the early recognition and treatment of stroke among community-dwelling individuals(3,13). In our sample, participants who provided concordant descriptors of stroke tended to describe the brain as the damaged end-organ or describe the underlying mechanisms that lead to stroke, rather than describe the physical symptoms associated with stroke. This may reflect the ways in which clinicians inform patients about stroke. It is possible that clinicians over-emphasize disease mechanism at the expense of educating patients on how to recognize symptoms of stroke. Health professionals tend to learn using a 'medical model' where the emphasis is on knowledge acquisition relating to disease mechanisms, pathology, and anatomy, rather than patient symptoms or experiences. In contrast, lay-people tend to learn through the 'health belief model', where the emphasis is on individual experiences and feelings (e.g. symptoms) and identifying behavioral or environmental triggers to which symptoms can be attributed(10). In this model, behavior is influenced by perceived susceptibility to disease, as interpreted and understood by the individual(10,22). These differences in learning perspectives could contribute to a communication mismatch during clinician-patient encounters(23). People with limited literacy or who are less proficient in English depend heavily on verbal communication from their providers, have less ability to obtain supplemental educational information from written sources, and are at particular risk for misunderstanding information they receive from the healthcare system(22).

Only one-third of subjects spontaneously volunteered accurate descriptions of at least one symptom of stroke, and most tended to describe paralysis as the presenting symptom. Acute facial paresthesia, unilateral arm drift, and abnormal speech have been considered the most accurate and reliable presenting symptoms of stroke(24). Prior research has shown that well over half of people with strokes who call for ambulance assistance fail to recognize that their symptoms were indicative of stroke, contributing to delay in pre-hospital and post-emergency care(13, 25,26). Our findings reinforce the importance of preparing high-risk patients for the variety of ways in which acute stroke can present, for example, using easily remembered mnemonics (27).

Attempts at improving the general public's awareness of stroke symptoms and stroke risk factors have had, at best, modest effects. Community education about stroke using television advertisements have been linked to increased awareness of stroke symptoms in certain regions (28–30). However, studies have also found that information penetrance was less among people with low education, the elderly, and racial/ethnic minorities, and that information retention waned over time(3,30–32). Current public health initiatives may therefore contribute to widening disparities in stroke knowledge by failing to target groups who are at particularly high risk for stroke. If public health campaigns fail to adequately address the communication needs of individuals with limited literacy, existing disparities in stroke prevention, recognition, and care may be even further exacerbated(3,33).

There are several limitations to our study. There were only two open-ended questions about warfarin and stroke and so we were unable to explore subjects' perceptions of their indication for warfarin and understanding of stroke in great depth. As such, we cannot state definitively that lack of information in their responses indicated complete lack of knowledge. We obtained measurements of literacy only on those patients who spoke English or Spanish, as the s-

TOFHLA has not been developed and/or validated in other languages. Similarly, while we employed the term ‘stroke-related health literacy’ as an aggregate outcome of the questions about warfarin indication and stroke knowledge relevant for this particular study population, we acknowledge that we took liberties in applying this concept to our study. Similarly, our operationalization of the construct of stroke-related health literacy has not been formally validated, and we do not know whether increasing patient stroke-related health literacy would lead to improvements in behavior and/or outcomes. Our study was carried out at a single center and involved low-income, ethnically and linguistically diverse populations taking warfarin, limiting overall generalizability. Finally, our study enrolled individuals taking warfarin to prevent stroke by virtue of having atrial fibrillation or a prosthetic heart valve, a subset of very high-risk people who had almost certainly received ongoing counseling about their risk for stroke and had weighed risks and benefits when opting to take warfarin on an ongoing basis. As such, our sample may overestimate the stroke-related health literacy of all patients with atrial fibrillation. It is possible that patients with similar risk factors who did not choose to be on warfarin may have even lower levels of stroke-related health literacy. Lack of knowledge of and/or perceived susceptibility to stroke could influence individuals’ decisions to engage in specific preventive therapies.

4.3. Practice implications

Our study has several implications for planning and prioritizing communication for both individual patient counseling as well as the public health context.

For individual clinician-patient interactions, our results suggest that clinicians attempting to initially engage or support patients in ongoing stroke prevention therapies should first educate patients about stroke, and specifically stroke symptoms and post-stroke states, rather than mechanisms of stroke. Once this knowledge has been mastered, clinicians should then draw a direct and explicit link between the therapy being offered (e.g. warfarin) and the anticipated reduction in the risk of stroke. Stroke prevention should be conveyed as the primary rationale for such treatment, rather than focusing on the biological mechanisms of action of warfarin. When and if a patient can demonstrate an understanding of the association between warfarin and stroke risk reduction, further discussions about risks and benefits associated with therapy are appropriate. Although the most effective strategies for improving comprehension in people with limited literacy are not entirely known, suggested interventions include prioritizing educational goals, simplifying information, using multimedia educational tools, and using interactive communication techniques(34). Clinicians can have patients iteratively repeat or ‘teach-back’ medical information in their own words so that comprehension can be assessed and information tailored(35–37). They can also frame discussions so that key concepts are highlighted, and should take care to avoid medical jargon(22,38). Programs where high-risk individuals regularly access the healthcare system, such as anticoagulation clinics or chronic disease/self-management support initiatives, represent important settings for collaborative public health and clinical communication interventions to improve stroke-related health literacy.

From a public health standpoint, general knowledge of stroke symptoms is low, possibly related to the heterogeneity, complexity and lack of specificity of neurologic symptoms, as well as the stigma associated with stroke. As early recognition is one of the most important aspects of stroke treatment and, as awareness of the sequelae of stroke can be a powerful facilitator of the uptake of preventive strategies, more effective ways to inform people about the variety of stroke symptoms and stroke syndromes are needed. Our finding that limited educational attainment and literacy are potent determinants of poor stroke-related health literacy provides further reinforcement for the need to obtain input from people who are at high risk for stroke to inform social marketing and other public health campaigns about stroke. People at risk for

stroke have indicated a desire for more practical information and individually tailored behavioral interventions(39). Video representations of disease have the potential to generate greater effects than narrative descriptions, effects that may be even more pronounced in racial/ethnic minority populations or those with low educational attainment(40,41). A recent study of patient values and wishes regarding late-stage Alzheimer's disease demonstrated the added value of images in conveying the meaning of health states that are often unfamiliar to the general population. Volandes AE et al. also demonstrated that individuals with limited literacy skills were disproportionately influenced by visual images, suggesting that they were better able to understand the consequences of advanced dementia(42). Providing visual information about the consequences of stroke may also be of benefit in improving stroke-related health literacy. The use of ethnic media events that employ celebrities, and 'reality' television shows, as well as integrated health education-adult literacy instructional models may potentially be health communication vehicles for at-risk populations(43–48). Our study demonstrates that inadequate understanding appears especially common among people with barriers to health communication, such as limited literacy or limited English proficiency, making improving health communication a promising target for interventions to better the quality of care.

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Figure 1.
Coding strategy for responses to "Why are you taking warfarin?"

Figure 2.
Coding strategy for responses to “What is a Stroke?”

Table 1
 Characteristics of 183 Subjects Taking Warfarin to Prevent Stroke

Characteristic	N (%) or mean $\pm$ SD
Age, years	61.3 $\pm$ 12.7
Female	85 (46.5)
Race	
Latino	49 (26.8)
Asian-Pacific Islander	78 (42.6)
White	30 (16.4)
African-American	20 (10.9)
Other	6 (3.3)
Most comfortable language	
English	47 (25.7)
Spanish	51 (27.9)
Cantonese/Mandarin	34 (18.6)
Tagalog	30 (16.4)
Other	21 (11.5)
Education	
$\leq 8^{\text{th}}$ grade	76 (41.5)
Some or all of high school	53 (29.0)
$\geq$ College	54 (29.5)
s-CASI* < 17	27 (14.8)
Years taking warfarin	4.1 $\pm$ 4.7
Indication for warfarin	
Atrial fibrillation	100 (54.6)
Prosthetic valve	25 (13.7)
Prior stroke	17 (9.3)
More than 1 indication	41 (22.4)

* s-CASI: short form Cognitive Abilities Screening Instrument

SD: standard deviation

Table 2

Representative Examples of How Subjects Characterized Their Indication for Warfarin Therapy and Described Stroke, Stratified by Measured Level of Literacy

“Why are you taking warfarin?”	Subjects with Inadequate or Marginal Literacy	Subjects with Adequate Literacy
Domain in which phrase was categorized		
<i>Concordant—medical problem</i>	Because I had a valve replaced To keep me stabilized-have skip in heartbeat Because of a fibrillation	Mitral artificial valve Lone atrial fibrillation Because I had a stroke Because of my heart; I came to the hospital with defibrillation and then they found I had a bunch of problems; heart palpitations
<i>Concordant—mechanism of warfarin</i>	To thin my blood Coumadin™ helps keep my blood thinner To thin my blood to make my blood flow better	Thinning of my blood It was prescribed for blood thinning To keep my blood thin
<i>Concordant—treatment goal</i>	I don't want to stop taking my pills because otherwise I will get clots To keep my valve working; blood needs to be thin else it clogs up To prevent stroke and other things To prevent coagulation or blood clots	So that my blood won't coagulate and prevent strokes If blood is not thin, valve wouldn't work To prevent blood clot I had no regular heartbeat and want to avoid blood clots going to the brain
<i>Discordant—other belief</i>	Blood is too thick and won't go through veins Helps blood get through the arteries For my blood to be thinner because of high blood pressure Blood is thick Because my doctor prescribes it, removes coagulation from skin Blood is not good	Because I'm 62 Blood is thick Hypertension, high cholesterol To prevent erratic heartbeat
“What is a stroke?”	Patients with inadequate or marginal literacy	Patients with adequate literacy
Domain in which phrase was categorized		
<i>Concordant—Brain Damage</i>	Head problems When the brain doesn't work right Brain gets numb	It affects your brain “Heart attack” in the brain Something in the brain
<i>Concordant—Symptoms of stroke</i>	A stroke is something like when you cannot talk Dizzy and then you feel something is wrong Half of the body not working very well Hit me in the head, having headache, tongue got twisted When you start feeling faint, when your hand starts to feel numb	When a part of your body is paralyzed, you can't move some body parts Heard people say it can make you paralyzed, you can't move and can't do anything, and in some cases, it can kill you Loss of equilibrium, muscle failure, speech failure, mild heart attack, causes you to lose control of the body Weakening of half of my body, interferes with my vision, a little bit forgetful
<i>Concordant—Mechanism of stroke</i>	Blood clot and blood can't circulate Blood decreases going to brain A clot in the blood passage	When a person is not receiving enough blood in his brain and blood vessel. And if there is a blockage in the blood vessel and damage to their nerve When a small particle breaks off from interior of artery, lodges itself in the brain, and causes brain damage from lack of blood flow Blood clot dislodges from arteries and moves to brain, cuts off oxygen supply to brain, affects left or right side of the brain Vascular blockage, decreased flow of oxygen to the brain
<i>Discordant—Other belief</i>	When blood is not running through your body When your heart stops Blood pressure is high and vein not working Problems with your heart; too much blood on your heart Your blood pressure is high and you become hard Chest pressure, short of breath When your blood is high, if your cholesterol is not good	A sudden failure of the heart to function normally, possibly due to blood clotting or high blood pressure or clotting of the arteries Blockage of one of the arteries or blood vessels, could be anywhere, prevents blood from going through the heart Heart attack Something to do with heart attack'

Table 3
How 183 Subjects Taking Warfarin to Prevent Stroke Characterized Their Indication For Warfarin and Described Stroke

“Why are you taking warfarin?”	N (%)
<i>Discordant Responses</i>	
I don't know	17 (9.3)
Other belief	61 (33.3)
<i>Concordant Responses</i>	
Identified underlying medical problem	96 (52.5)
Described the mechanism of warfarin	45 (24.6)
Described treatment goal of warfarin therapy	46 (25.1)
Mentioned stroke prevention as a goal of warfarin	17 (9.3)
Number of concordant domains	
One domain	95 (51.9)
Two domains	28 (15.3)
Three domains	12 (6.6)
“What is a stroke?”	N (%)
<i>Discordant Responses</i>	
I don't know	43 (23.5)
Other belief	31 (16.9)
<i>Concordant Responses</i>	
Brain damage	56 (30.6)
Symptoms of stroke	61 (33.3)
Mechanism of stroke	61 (33.3)
Number of concordant domains	
One domain	58 (31.7)
Two domains	51 (27.9)
Three domains	6 (3.3)

Table 4
Association of Literacy with How 146 Subjects Described Their Indication for Warfarin and Characterized Stroke

	Literacy			P value
	Inadequate n=76	Marginal n=18	Adequate n=52	
n (%)				
“Why are you taking warfarin?”				
Discordant responses				
I don’t know	10 (13.2)	0 (0.0)	2 (3.9)	0.07
Other belief	28 (36.8)	5 (27.8)	10 (19.2)	0.10
Concordant responses				
Identified underlying medical problem	33 (43.4)	10 (55.6)	35 (67.3)	0.03
Described the mechanism of warfarin	15 (19.7)	7 (38.9)	18 (34.6)	0.09
Described treatment goal of warfarin therapy	13 (17.1)	7 (38.9)	21 (40.4)	0.01
Mentioned stroke prevention as a goal of warfarin	5 (6.6)	3 (16.7)	8 (15.4)	0.21
Described at least one concordant aspect of warfarin indication	49 (64.5)	16 (88.9)	48 (92.3)	<0.01
“What is a stroke?”				
Discordant responses				
I don’t know	31 (40.8)	2 (11.1)	3 (5.8)	<0.01
Other belief	18 (23.7)	5 (27.8)	6 (11.5)	0.16
Concordant responses				
Brain damage	11 (14.5)	5 (27.8)	32 (61.5)	<0.01
Symptoms of stroke	18 (23.7)	5 (27.8)	18 (34.6)	0.40
Mechanism of stroke	14 (18.4)	6 (33.3)	31 (59.6)	<0.01
Described at least one concordant aspect of stroke	29 (38.2)	12 (66.7)	46 (88.5)	<0.01

Table 5
Multivariable Model of Associations Between Subject Characteristics and Discordant Responses For Full Cohort (n=183) and Subgroup with Measures of Literacy (n=146)

Adjusted odds ratio and 95% Confidence Interval		
	Predictors of discordant responses regarding warfarin	Predictors of discordant responses regarding stroke
Full Cohort		
Age (per year)	1.0 [1.0–1.1]	1.0 [0.99–1.04]
Female	0.8 [0.4–1.6]	0.9 [0.5–1.8]
Less than college education (vs. College educated)	3.3 [1.4–7.3]	2.5 [1.2–5.6]
Non-English speaking (vs. English-speaking)	2.5 [1.1–5.6]	0.7 [0.3–1.6]
s-CASI [*] score < 17	2.6 [0.9–7.3]	4.9 [1.7–14.5]
Years on warfarin (per year)	0.9 [0.8–0.9]	1.1 [1.0–1.1]
Subgroup with measures of literacy		
Age (per year)	1.0 [1.0–1.1]	1.0 [0.98–1.04]
Female	0.9 [0.4–1.8]	0.9 [0.4–2.0]
Non-English speaking (vs. English-speaking)	1.6 [0.6–4.0]	0.8 [0.3–2.1]
s-CASI score < 17	2.8 [0.9–1.2]	7.2 [1.5–35.1]
Years on warfarin (per year)	0.9 [0.8–1.0]	1.0 [0.9–1.1]
Literacy		
Inadequate vs. Adequate	2.2 [0.8–5.7]	5.8 [2.1–15.6]
Inadequate vs. Marginal	2.5 [0.7–8.9]	2.1 [0.7–6.5]

* s-CASI: short form Cognitive Abilities Screening Instrument