

UCSF

UC San Francisco Previously Published Works

Title

Health Literacy and Treatment Satisfaction Among Patients with Venous Thromboembolism.

Permalink

<https://escholarship.org/uc/item/2fc4p0mc>

Journal

Journal of General Internal Medicine, 38(7)

Authors

Mefford, Matthew

Zhou, Hui

Fan, Dongjie

et al.

Publication Date

2023-05-01

DOI


10.1007/s11606-022-07852-3

Peer reviewed



ORIGINAL RESEARCH

Health Literacy and Treatment Satisfaction Among Patients with Venous Thromboembolism

Matthew T. Mefford, PhD¹ , Hui Zhou, PhD^{1,2}, Dongjie Fan, MSPH³, Margaret C. Fang, MD, MPH⁴, Priya A. Prasad, MD⁴, Alan S. Go, MD, PhD^{2,3,5,6}, Cecilia Portugal, MPH¹, John M. Chang, MPH¹, and Kristi Reynolds, PhD^{1,2}

¹Department of Research and Evaluation, Kaiser Permanente Southern California, Pasadena, CA, USA; ²Department of Health Systems Science, Kaiser Permanente Bernard J. Tyson School of Medicine, Pasadena, CA, USA; ³Division of Research, Kaiser Permanente Northern California, Oakland, CA, USA; ⁴Division of Hospital Medicine, University of California, San Francisco, San Francisco, CA, USA; ⁵Department of Medicine and Department of Epidemiology and Biostatistics, University of California, San Francisco, San Francisco, CA, USA; ⁶Departments of Medicine, Health Research and Policy, Stanford University, Palo Alto, CA, USA.

BACKGROUND: Venous thromboembolism (VTE) treatment requires complex management, and patients with limited health literacy (HL) may perceive higher burden and lower benefits associated with their treatment.

OBJECTIVE: To examine the association of HL with treatment satisfaction among patients with VTE.

DESIGN: Retrospective cohort study

PARTICIPANTS: Kaiser Permanente Southern and Northern California members who were taking oral anti-coagulants (OAC) for incident VTE between 2015 and 2018 were surveyed.

Main Measures

HL was assessed using a 3-item HL assessment and dichotomized as having adequate or limited HL. High treatment burden and low treatment benefit were defined as Anti-Clot Treatment Scale (ACTS) scores below the 25th percentile of the distributions for ACTS Burdens and Benefits survey components, respectively. Using Poisson regression, multivariable adjusted risk ratios (RR) and 95% confidence intervals (CI) were calculated for the association of HL with high treatment burden and low treatment benefits.

RESULTS: Among 2154 respondents, 397 (18.4%) had limited HL. Patients with limited vs adequate HL were older (47.9% vs 27.5% aged \geq 75 years, $p < 0.001$), more likely to use a non-English language when discussing their health (10.8% vs 1.7%, $p < 0.001$), to have less than high school education (10.1% vs 1.7%, $p < 0.001$), and to self-rate their health as fair or poor (47.6% vs 25.5%, $p < 0.001$). After multivariable adjustment, patients with limited HL were more likely to have higher perceived treatment burden (RR 1.24, 95% CI 1.07, 1.45) and lower perceived treatment benefits (RR 1.21, 95% CI 1.08, 1.37).

CONCLUSIONS: Limited HL was associated with lower OAC treatment satisfaction, though absolute differences in satisfaction scores were small. Further examination of the intersection of HL with VTE treatment satisfaction and compliance among older and non-English speaking patients is warranted.

KEY WORDS: venous thromboembolism; health literacy; treatment; satisfaction.

J Gen Intern Med 38(7):1585–92

DOI: 10.1007/s11606-022-07852-3

© The Author(s), under exclusive licence to Society of General Internal Medicine 2022

Health literacy (HL) is an individual's ability to obtain and process health information needed to make health decisions, and is fundamental to their quality of health care.¹ A 2006 report from the US Department of Education National Center for Education Statistics indicated that 12% of US adults had proficient HL while nearly half of US adults have difficulty interpreting and using healthcare information.² Several organization-level action plans have since been proposed to improve HL screening and address barriers to healthcare access and disease management caused by HL.^{3,4} Furthermore, HL screening is important to understand the connection between a patient's ability to understand complex health information and how they manage their health. Higher levels of HL have been associated with high levels of patient satisfaction regarding provider communication and treatment.^{5,6} In contrast, low HL is associated with receiving fewer preventive services, worse medication adherence and health outcomes, and higher risk of death.^{7–10} Barriers to care including recognition, management, and prevention are noted similarly among cardiovascular, renal, diabetes, and mental health conditions among individuals with low HL.^{11–14}

Venous thromboembolism (VTE) is a common cardiovascular condition in the US that confers significant morbidity and mortality.^{15,16} Treatment for VTE includes therapeutically dosed anticoagulation for a fixed period, often an initial course of 3–6 months, followed by longer-term use depending on the complexity of a patient's condition, recurrent VTE episodes, or high-predicted risk of subsequent VTE.¹⁷ Treatment options include the oral vitamin K antagonist, warfarin, which requires frequent

Received May 24, 2022

Accepted October 20, 2022

Published online November 3, 2022

monitoring via blood tests and potential dose changes, and direct oral anticoagulants (DOACs), which are fixed-dose regimens. Although DOACs do not require routine laboratory monitoring, like warfarin they can increase the risk of bleeding, and optimal management of VTE with either regimen requires a clear understanding of these risks. A prior study showed that low HL was associated with a greater likelihood of reporting significant barriers to VTE care including medication or healthcare costs, transportation issues, or social support.¹⁸ However, it is unknown if HL influences patient perceptions of their VTE treatment. If patients with lower HL perceive their treatment as burdensome, this may increase the likelihood of treatment nonadherence and adverse outcomes. The goal of the current study was to examine the association between HL and perceptions of treatment satisfaction, as assessed by the Anti-Clot Treatment Scale© (ACTS), among patients with VTE.

METHODS

Data Access

Anonymized data that support the findings of this study may be made available from the investigative team in the following conditions¹: agreement to collaborate with the study team on all publications,² provision of external funding for administrative and investigator time necessary for this collaboration,³ demonstration that the external investigative team is qualified and has documented evidence of training for human subjects protections, and⁴ agreement to abide by the terms outlined in data use agreements between institutions.

Setting

We included adults enrolled in Kaiser Permanente Southern California (KPSC) and Kaiser Permanente Northern California (KPNC), two large, integrated healthcare delivery systems providing care for >9 million individuals, and is representative of the sociodemographically diverse population of California.^{19,20} Members' receipt of outpatient, inpatient, laboratory, and pharmacy services are tracked in each site's electronic health record (EHR) system. Services performed outside of KP-owned facilities are systematically tracked through submitted billing claims. The institutional review boards at KPSC and KPNC reviewed and approved the current study.

Study Population

Adults ≥ 18 years of age, who completed an initial treatment course (e.g., 3 months) of warfarin or DOAC after an incident diagnosis of acute VTE that occurred between January 1, 2010, and December 31, 2018, were identified ($n=39,605$). Incident VTE was defined as a clinical encounter associated with a primary or secondary discharge diagnosis of VTE according to the *International Classification of Diseases Ninth Revision* (ICD-9) or *Tenth Revision* (ICD-10), and without a prior VTE diagnosis or oral anticoagulant prescription in the 4 years prior.

Anticoagulant prescriptions were identified from health plan outpatient pharmacy dispensing databases (warfarin and DOAC). Data on subject demographics (age, sex, race/ethnicity, preferred language, income, and education) were obtained from the EHR. This cohort has been described in detail previously.²¹ A subset of patients who had their incident VTE diagnosis between January 1, 2015, and June 30, 2018, were invited to complete a survey on anticoagulant treatment satisfaction ($n=12,737$). The survey was completed in English, Spanish, and Mandarin via a mailed questionnaire or by telephone and included the ACTS, a validated 17-item patient-reported scale.²² Patients were asked to complete the ACTS only if they had been taking anticoagulants within the past 4 weeks, to prevent recall bias. The surveys also asked about patients' income, education, self-rated health, and HL. Overall, 5017 patients responded to the survey; respondents and non-respondents were similar with respect to baseline demographic characteristics (data not shown). After excluding patients who were missing information to determine health literacy status ($n=251$), who were not taking anticoagulants in the 4 weeks prior to survey administration ($n=2604$), or who answered less than 50% of ACTS questions ($n=12$), the final analytic sample was 2154 (Fig. 1).

Outcomes

The primary outcome of interest was anticoagulant treatment satisfaction measured by the ACTS. The ACTS is divided into two sub-scales, ACTS Burdens (assessing challenges with treatment) and ACTS Benefits (assessing confidence and reassurance in treatment) scales. ACTS Burdens is reverse coded on a 5-point Likert scale and is the sum of 12 items (score range 12 to 60). ACTS Benefits is coded from 1 to 5 and is the sum of 3 items (score range 3 to 15). Higher scores denote greater satisfaction with treatment. We calculated the ACTS scores according to the developers' guidelines.²² Given ACTS score distributions were skewed, we created categories of "high burden" and "low benefit," defined as scores below the 25th percentile of the analytic population distribution of the Burdens and Benefits scales (score ≤ 48 and score ≤ 9 , respectively), consistent with prior studies.²³

Exposure

Health literacy was assessed using 3 questions from the patient survey that included¹ "How often has someone (like a family member, friend, hospital clinic worker, or caregiver) helped you read hospital or other medical materials?" with the response options of "None of the time," "A little of the time," "Some of the time," "Most of the time," and "All of the time"²; "How often do you have problems learning about your medical condition because of difficulty understanding written information?" with the same response options as the first question; and³ "How confident are you filling out forms by yourself?" with the response options of "Extremely," "Quite a bit," "Somewhat," "A little bit," and "Not at all." For each of these questions, response options were scored from 0 to 4, with higher scores representing lower HL. The scores from each of

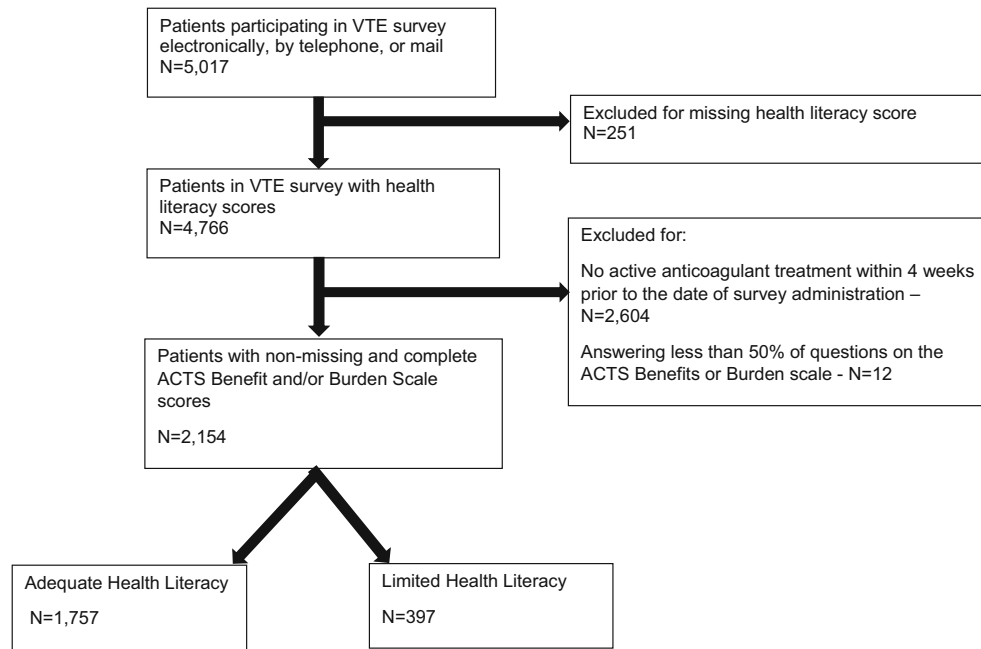


Fig. 1 Participant flow chart. Abbreviations: ACTS, Anti-Clot Treatment Scale; VTE, venous thromboembolism

these 3 questions were summed (score range 0 to 12) and the summed score was categorized into “adequate health literacy” (score 0 to 2) and “limited health literacy” (score ≥ 3). This method of dichotomization has been previously identified to optimally distinguish between limited and adequate HL.^{24–26}

Covariates

Age at the time of survey administration (≤ 54 , 55–64, 65–74, 75–84, ≥ 85 years), sex, and race/ethnicity (non-Hispanic [NH] white, NH black, Hispanic, Asian/Pacific Islander/Multiple/Other/Unknown), VTE type, and treatment type were collected from the EHR. Survey-collected covariates included preferred language (English, Other/Unknown) when talking or learning about own health, education (less than high school [HS], HS graduate or graduate equivalency degree, some college/technical school, bachelor’s degree, graduate degree, unknown/missing), household income ($< \$15k$, $\$15k–\$25k$, $\$25k–\$35k$, $\$35k–\$50k$, $\$50k–\$65k$, $\$65k–\$80k$, $\$80k–\$100k$, $\$100k–\$150k$, $> \$150k$), marital status (married, not married but committed, widowed, single/divorced/separated, missing), and self-rated health (excellent, very good, good, fair, poor, missing).

Statistical Analysis. Baseline characteristics of patients who completed their survey were compared between patients with adequate and limited HL. Chi-square statistics were calculated to test for differences in categorical variables by HL status. Frequencies of responses to each HL question and mean (standard deviations) and median (25th and 75th percentile) ACTS Burdens and Benefits scores were calculated overall and compared by HL status using the Student’s *t*-test for mean differences and the Wilcoxon rank-sum test for median differences. To determine the association between HL status and low perceived treatment

benefits, we used Poisson regression with robust standard errors to estimate relative risks (RR) and 95% confidence intervals (CI) sequentially adjusted for covariates of interest. Model 1 adjusted for age, sex, and race/ethnicity. Model 2 adjusted for model 1 covariates plus self-rated health. Given the complexity of warfarin vs DOAC treatment management, to test if the association between HL and low perceived treatment benefit was confounded or different by treatment type, model 3 adjusted for model 2 covariates plus treatment type. In a stratified analysis, the association for HL and low treatment benefit was conducted for those taking DOAC and warfarin, separately. Analyses were repeated as described above to calculate adjusted RR and 95% CI for the association between HL status and high perceived treatment burden. In a sensitivity analysis, we repeated these methods limiting the study population to individuals who noted English as their preferred language to determine if removing language as a potential barrier to the exchange of health information between patients and providers would appreciably change our findings.

Finally, we calculated mean differences and 95% CI for the association between HL status and the ACTS Benefits Scale and ACTS Burden Scale, separately using a generalized linear model following sequential adjustment as described previously. All statistical tests were 2-sided and $p < 0.05$ was considered statistically significant. All analyses were conducted using SAS Enterprise Guide 7.1 (Cary, NC).

RESULTS

Baseline Characteristics

Among 2154 patients, a majority were ≥ 65 years of age (61.4%), male (57.1%), NH white (71.3%), and over half of VTE types identified were pulmonary embolism (54.6%) (Table 1). In total,

397 (18.4%) were categorized as having limited HL. The distribution of patient responses to HL questions is listed in Table S1. Patients with limited vs adequate HL were more likely to be older (18.9% vs 5.8% ≥ 85 years of age, respectively, $p < 0.001$), less

likely to be NH white (62.2% vs 73.4%, respectively, $p < 0.001$), and less likely to choose English as their preferred language for discussing health information (89.2% vs 98.3%, respectively, $p < 0.001$) (Table 1). Patients with limited HL also had lower

Table 1 Baseline Characteristics by Health Literacy Status in Adults with Incident VTE Treated with Oral Anticoagulation

	Overall N= 2154	Adequate Literacy N=1757	Limited Literacy N= 397	p-value
Age at survey, years, n (%)				
≤ 54	373 (17.3)	322 (18.3)	51 (12.8)	<0.001
55–64	458 (21.3)	398 (22.7)	60 (15.1)	
65–74	649 (30.1)	553 (31.5)	96 (24.2)	
75–84	497 (23.1)	382 (21.7)	115 (29.0)	
≥ 85	177 (8.2)	102 (5.8)	75 (18.9)	
Male, n (%)	1231 (57.1)	997 (56.7)	234 (58.9)	0.42
Race/ethnicity, n (%)				
NH White	1536 (71.3)	1289 (73.4)	247 (62.2)	<0.001
NH Black	215 (10.0)	170 (9.7)	45 (11.3)	
Hispanic	229 (10.6)	162 (9.2)	67 (16.9)	
Asian/Pacific Islander /Multiple/Other/Missing	174 (8.1)	136 (7.7)	38 (9.6)	
Index year, n (%)				
2015	597 (27.7)	487 (27.7)	110 (27.7)	0.62
2016	781 (36.3)	627 (35.7)	154 (38.8)	
2017	537 (24.9)	444 (25.3)	93 (23.4)	
2018	239 (11.1)	199 (11.3)	40 (10.1)	
Survey completion				
Partial	20 (0.9)	13 (0.7)	7 (1.8)	0.05
Complete	2134 (99.1)	1744 (99.3)	390 (98.2)	
Preferred language, n (%)				
English	2081 (96.6)	1727 (98.3)	354 (89.2)	<0.001
Other/unknown	73 (3.4)	30 (1.7)	43 (10.8)	
Education, n (%)				
Less than high school	69 (3.2)	29 (1.7)	40 (10.1)	<0.001
High school graduate or equivalent	293 (13.6)	184 (10.5)	109 (27.5)	
Some college or technical school	859 (39.9)	712 (40.5)	147 (37.0)	
Bachelor's degree	474 (22.0)	425 (24.2)	49 (12.3)	
Graduate degree	405 (18.8)	368 (20.9)	37 (9.3)	
Unknown/missing	54 (2.5)	39 (2.2)	15 (3.8)	
Total annual household income, n (%)				
< \$15,000	83 (3.9)	46 (2.6)	37 (9.3)	<0.001
\$15,000–\$25,000	144 (6.7)	102 (5.8)	42 (10.6)	
\$25,001–\$35,000	142 (6.6)	101 (5.7)	41 (10.3)	
\$35,001–\$50,000	196 (9.1)	163 (9.3)	33 (8.3)	
\$50,001–\$65,000	199 (9.2)	162 (9.2)	37 (9.3)	
\$65,001–\$80,000	203 (9.4)	166 (9.4)	37 (9.3)	
\$80,001–\$100,000	220 (10.2)	193 (11.0)	27 (6.8)	
\$100,001–\$150,000	296 (13.7)	271 (15.4)	25 (6.3)	
>\$150,000	244 (11.3)	229 (13.0)	15 (3.8)	
Declined to answer	343 (15.9)	271 (15.4)	72 (18.1)	
Missing	84 (3.9)	53 (3.0)	31 (7.8)	
Marital status, n (%)				
Married	1316 (61.1)	1092 (62.2)	224 (56.4)	<0.001
Not married but committed	100 (4.6)	85 (4.8)	15 (3.8)	
Widowed	217 (10.1)	153 (8.7)	64 (16.1)	
Single, divorced, or separated	478 (22.2)	397 (22.6)	81 (20.4)	
Missing	43 (2.0)	30 (1.7)	13 (3.3)	
Self-reported health status, n (%)				
Excellent	118 (5.5)	112 (6.4)	6 (1.5)	<0.001
Very good	486 (22.6)	444 (25.3)	42 (10.6)	
Good	905 (42.0)	745 (42.4)	160 (40.3)	
Fair	496 (23.0)	364 (20.7)	132 (33.2)	
Poor	141 (6.5)	84 (4.8)	57 (14.4)	
Missing	8 (0.4)	8 (0.5)	0 (0.0)	
VTE type, n (%)				
Pulmonary embolism	1177 (54.6)	970 (55.2)	207 (52.1)	0.25
Lower extremity DVT	826 (38.3)	663 (37.7)	163 (41.1)	
Upper extremity DVT	68 (3.2)	52 (3.0)	16 (4.0)	
Other VTE/unknown	83 (3.9)	72 (4.1)	11 (2.8)	
Initial treatment, n (%)				
Warfarin	1208 (56.1)	956 (54.4)	252 (63.5)	0.001
DOAC	946 (43.9)	801 (45.6)	145 (36.5)	

Abbreviations: API, Asian/Pacific Islander; DOAC, direct oral anticoagulant; DVT, deep vein thrombosis; NH, non-Hispanic; VTE, venous thromboembolism

levels of education (37.6% vs 12.2% with high school degree or less, respectively, $p<0.001$), annual household income (9.3% vs 2.6% with $< \$15,000$, respectively, $p<0.001$), and were more likely to report lower self-rated health (47.6% vs 25.5% reporting fair or poor health, respectively, $p<0.001$). A higher proportion of VTE patients with limited vs adequate HL were taking warfarin (63.5% vs 54.4%, respectively, $p=0.001$) to treat their VTE.

Mean and median ACTS Benefit and Burden scores are listed in Table 2. Overall mean ACTS Benefit and Burden scores were 10.3 (out of a maximum score of 15) and 51.6 (out of a maximum score of 60), respectively. Patients with limited vs adequate literacy HL had a lower mean ACTS Benefit score (9.6 vs 10.4, respectively, $p<0.001$) and ACTS Burden score (50.1 vs 52.0, respectively, $p=0.004$). Median differences in ACTS Benefit and Burden scores were similarly lower among patients with limited HL. Unadjusted and multivariable adjusted mean differences are presented in Table S2. After multivariable adjustment for age, sex, race/ethnicity, self-rated health, and treatment type, adults with limited HL had statistically significantly lower ACTS Benefits scores (difference = -0.5 , 95% CI $-0.8, -0.1$) and ACTS Burden scores (difference = -1.3 , 95% CI $-2.1, -0.4$).

In unadjusted analysis, limited HL was associated with a higher risk of having low perceived treatment benefits compared with patients who had adequate HL (RR 1.34, 95% CI 1.19, 1.50) (Table 3). After multivariable adjustment, the RR of limited HL for low perceived treatment benefits was 1.21 (95% CI 1.08, 1.37). Similarly, in unadjusted analysis, compared with adequate HL, limited HL was associated with having high perceived treatment burden (RR 1.43, 95% CI 1.22, 1.68). After multivariable adjustment, the RR of limited HL for having a high perceived treatment burden was 1.24 (95% CI 1.07, 1.45). These results were consistent when stratified by DOAC users (Table S3) and warfarin users (Table S4). In a sensitivity analysis limited to patients who preferred using English to communicate about their health information ($n=2081$) and controlling for age, sex, race/ethnicity, self-rated health, and treatment type, patients with limited HL were more likely to have low perceived treatment benefits (adjusted RR 1.22, 95% CI 1.08, 1.38) and high perceived treatment burdens (adjusted RR 1.20, 95% CI 1.01, 1.42) compared with those who had adequate HL, which is consistent with the overall study population (Table S5).

Table 3 Relative Risk and 95% Confidence Intervals for the Association Between Perceived Low Treatment Benefit and High Treatment Burden

	Limited vs. adequate health literacy	p-value
Low treatment benefit		
Unadjusted	1.34 (1.19, 1.50)	<0.001
Model 1: age, sex, race/ethnicity	1.34 (1.20, 1.51)	<0.001
Model 2: model 1 + self-rated health	1.22 (1.08, 1.37)	0.001
Model 3: model 2 + anticoagulant type	1.21 (1.08, 1.37)	0.002
High treatment burden		
Unadjusted	1.43 (1.22, 1.68)	<0.001
Model 1: age, sex, race/ethnicity	1.53 (1.30, 1.78)	<0.001
Model 2: model 1 + self-rated health	1.26 (1.08, 1.48)	0.003
Model 3: model 2 + anticoagulant type	1.24 (1.07, 1.45)	0.006

DISCUSSION

Among a diverse patient population with incident VTE and recent OAC therapy use in KPSC and KPNC, those with limited HL were older and less likely to be NH white, and had lower levels of education and household income. These patients were also less likely to choose English as their preferred language to communicate about health information. After adjustment for patient demographic characteristics, self-rated health, and treatment type, patients with limited HL perceived less benefit and a higher burden of their treatment (i.e., lower overall treatment satisfaction) compared with patients with adequate HL, though the absolute magnitude of differences was small. This was consistent overall, and among the subset of patients who chose English as their preferred language.

According to a 2003 National Assessment of Adult Literacy, 36% of 30,000 households surveyed by the US Department of Education were identified as having basic or below-basic HL skills.²⁷ The prevalence of limited HL was higher for individuals with low educational attainment, older aged individuals, racial/ethnic minorities, and people with chronic diseases.²⁸ This is consistent with observations from the current study where imbalances by age, race/ethnicity, education, and income were detected among VTE patients with limited vs adequate HL. For patients with VTE, the risk of recurrent

Table 2 ACTS Benefit and Burden Scores by Health Literacy Status

	Overall	Adequate literacy	Limited literacy	p-value
ACTS Benefit Scale	N=2146	N=1753	N=393	
Mean (std)	10.3 (3.0)	10.4 (3.0)	9.6 (3.2)	<0.001
Median (25th, 75th percentile)	11.0 (9.0, 12.0)	11.0 (9.0, 12.0)	9.0 (8.0, 12.0)	<0.001
ACTS Burden Scale	N=2149	N=1754	N=395	
Mean (std)	51.6 (8.0)	52.0 (7.7)	50.1 (9.3)	0.004
Median (25th, 75th percentile)	54.0 (48.0, 58.0)	54.0 (49.0, 58.0)	53.0 (45.0, 58.0)	0.004

Abbreviations: ACTS, Anti-Clot Treatment Scale; Std, standard deviation

thrombotic events is 5–7% per year,²⁹ largely dependent on patient factors.³⁰ Ensuring these individuals receive adequate education pertaining to the risks and benefits or treatments, and understand the care and management required for their condition is of the utmost clinical importance. Prior studies have noted that patient knowledge of anticoagulants was positively associated with better therapy maintenance, and insufficient education regarding anticoagulants was predictive of major bleeding events; however, findings have been mixed.^{31–34} For patients with limited HL, this can be challenging given a general apprehension to express misunderstanding to their healthcare providers.³⁵ Given the complexity of VTE care, screening for HL, asking about language preferences, and providing simple, easy to follow treatment instructions may improve outcomes.^{36,37}

ACTS scores in the current study were lower than a prior study based on the EINSTEIN randomized clinical trial (RCT).²² Patients from RCTs may be different from the general population due to stringent selection criteria, highlighting the importance of conducting evaluations in real-world settings. Overall, limited HL was associated with lower treatment satisfaction as measured by the ACTS Benefits and Burdens scales. In prior studies, low treatment satisfaction and low HL were associated with greater anticoagulant treatment noncompliance or worse persistence.^{38,39} Nonadherence to anticoagulant treatment has been associated with higher healthcare expenditures and adverse outcomes including hospitalization and death.^{40,41} However, a prior study found that HL was not associated with differences in anticoagulation adherence.³⁴ Though measures of adherence and subsequent outcomes including bleeding, recurrent VTE, or death were not examined for the current study, this is important in future studies.

In the current study, we observed no differences in the association of HL and perceived treatment benefits or burdens between patients receiving warfarin vs DOACs. However, we observed a higher proportion of VTE patients with limited HL taking warfarin. It is possible that individuals with limited HL have more comorbidities including kidney disease that led to preferential use of warfarin. While comorbidities were not assessed in the current study, this may be important for future evaluations. Prior studies have indicated that adherence to warfarin is low in many patients, and that warfarin users were less satisfied with their treatment compared to DOAC.^{42,43} Adherence to DOACs among patients with new-onset VTE is higher, with a prior observational study reporting adherence over 90% after 18 months.⁴⁴ Discussing the benefits of OAC treatment as prescribed is important to avoid potential adherence-related complications regardless of treatment type.

Strengths of the current study include participation from patients in two large, diverse integrated healthcare delivery systems. We used validated survey instruments to assess both HL and perceptions of treatment benefit and burden. We also acknowledge some limitations. Patients included in the study were insured and results may not be fully generalizable to less-insured populations. Patients who were not actively taking anticoagulant treatment within 4 weeks prior to the survey administration were excluded. Some eligible patients declined or did not respond and it is possible that this group of individuals may be different with respect to HL. However, the survey was offered by mail and telephone, and a larger portion of individuals with limited vs adequate HL completed via telephone (16% vs 7%, respectively). Next, individuals with worse disease or more comorbidity while on anticoagulation may have more difficulty with treatment and less satisfaction, though comorbidities and outcomes were not available for this study. There is no research examining ACTS validity across varying levels of HL. Despite this, scores in the current study are similar among patients with adequate and limited HL and individuals excluded for missingness were minimal. We did not collect length of anticoagulation therapy use or measure adherence to VTE treatments, and can only speculate how HL and treatment satisfaction may impact patient compliance. Finally, there is the potential for unmeasured confounding. However, for the association of HL with treatment benefit and treatment burden, we calculated E-values of 1.71 and 1.79, respectively, which suggests there is a low likelihood any unmeasured confounders were missed to explain away the RR observed in our main analysis.

In conclusion, limited HL is associated with lower anticoagulant treatment satisfaction. Further examination of the intersection of HL with VTE treatment satisfaction and compliance among older, less educated, and non-English speaking patients is warranted.

Acknowledgements: The authors thank the patients of Kaiser Permanente for helping to improve care through the use of information collected through our electronic health record systems.

Corresponding Author: Matthew T. Mefford, PhD; Department of Research and Evaluation, Kaiser Permanente Southern California, Pasadena, CA, USA (e-mail: matthew.t.mefford@kp.org).

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s11606-022-07852-3>.

Funding Research reported in this article was funded through a Patient-Centered Outcomes Research Institute (PCORI) Award (NOACs-1510-32651) and the National Heart, Lung, and Blood Institute of the National Institutes of Health (K24HL141354). The content is solely the responsibility of the authors and does not necessarily represent the official views of PCORI or the National Institutes of Health.

Declarations:

Conflict of Interest: Dr. Go has received research grants through his institution from the National Heart, Lung and Blood Institute; Bristol Meyers Squibb; and Janssen Research & Development. Dr. Prasad reports personal fees from EpiExcellence, LLC, outside the submitted work.

REFERENCES

- Sorensen K, Van den Broucke S, Fullam J, Doyle G, Pelikan J, Slonska Z, et al. Health literacy and public health: a systematic review and integration of definitions and models. *BMC Public Health*. 2012;12:80. <https://doi.org/10.1186/1471-2458-12-80>
- National Center for Education Statistics. The health literacy of America's adults: results from the 2003 National Assessment of Adult Literacy. 2006.
- Baur C, Harris L, Squire E. The U.S. National Action Plan to Improve Health Literacy: A Model for Positive Organizational Change. *Stud Health Technol Inform*. 2017;240:186-202.
- In: Nielsen-Bohlman L, Panzer AM, Kindig DA, editors. *Health Literacy: A Prescription to End Confusion*. Washington (DC) 2004.
- Yim CK, Shumate L, Barnett SH, Leitman IM. Health literacy assessment and patient satisfaction in surgical practice. *Ann Med Surg (Lond)*. 2018;35:25-8. <https://doi.org/10.1016/j.amsu.2018.08.022>
- Altin SV, Stock S. The impact of health literacy, patient-centered communication and shared decision-making on patients' satisfaction with care received in German primary care practices. *BMC Health Serv Res*. 2016;16:450. <https://doi.org/10.1186/s12913-016-1693-y>
- Baker DW, Wolf MS, Feinglass J, Thompson JA, Gazmararian JA, Huang J. Health literacy and mortality among elderly persons. *Arch Intern Med*. 2007;167(14):1503-9. <https://doi.org/10.1001/archinte.167.14.1503>
- Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Crotty K. Low health literacy and health outcomes: an updated systematic review. *Ann Intern Med*. 2011;155(2):97-107. <https://doi.org/10.7326/0003-4819-155-2-201107190-00005>
- Cho YI, Lee SY, Arozullah AM, Crittenden KS. Effects of health literacy on health status and health service utilization amongst the elderly. *Soc Sci Med*. 2008;66(8):1809-16. <https://doi.org/10.1016/j.socscimed.2008.01.003>
- Roh YH, Lee BK, Park MH, Noh JH, Gong HS, Baek GH. Effects of health literacy on treatment outcome and satisfaction in patients with mallet finger injury. *J Hand Ther*. 2016;29(4):459-64. <https://doi.org/10.1016/j.jht.2016.06.004>
- Cajita MI, Cajita TR, Han HR. Health literacy and heart failure: a systematic review. *J Cardiovasc Nurs*. 2016;31(2):121-30. <https://doi.org/10.1097/JCN.0000000000000229>
- Cavanaugh KL. Health literacy in diabetes care: explanation, evidence and equipment. *Diabetes Manag (Lond)*. 2011;1(2):191-9. <https://doi.org/10.2217/dmt.11.5>
- Jain D, Green JA. Health literacy in kidney disease: review of the literature and implications for clinical practice. *World J Nephrol*. 2016;5(2):147-51. <https://doi.org/10.5527/wjn.v5.i2.147>
- Tambling RR, D'Aniello C, Russell BS. Mental health literacy: a critical target for narrowing racial disparities in behavioral health. *Int J Ment Health Addict*. 2021;1-15. <https://doi.org/10.1007/s11469-021-00694-w>
- Centers for Disease Control and Prevention. Venous thromboembolism in adult hospitalizations - United States, 2007-2009. *MMWR Morb Mortal Wkly Rep*. 2012;61(22):401-4.
- The Lancet Haematology. Thromboembolism: an under appreciated cause of death. *Lancet Haematol*. 2015;2(10):e393. [https://doi.org/10.1016/S2352-3026\(15\)00202-1](https://doi.org/10.1016/S2352-3026(15)00202-1)
- Ortel TL, Neumann I, Ageno W, Beyth R, Clark NP, Cuker A, et al. American Society of Hematology 2020 guidelines for management of venous thromboembolism: treatment of deep vein thrombosis and pulmonary embolism. *Blood Adv*. 2020;4(19):4693-738. <https://doi.org/10.1182/bloodadvances.2020001830>
- Pulleyn T, Kim K, Witt DM, Feehan M, Munger MA. Understanding patients' care barriers in the treatment of venous thromboembolism. *J Thromb Thrombolysis*. 2019;48(1):35-41. <https://doi.org/10.1007/s11239-019-01880-3>
- Koebnick C, Langer-Gould AM, Gould MK, Chao CR, Iyer RL, Smith N, et al. Sociodemographic characteristics of members of a large, integrated health care system: comparison with US Census Bureau data. *Perm J*. 2012;16(3):37-41. <https://doi.org/10.7812/tpp/12-031>
- Gordon N, Lin T. The Kaiser Permanente Northern California Adult Member Health Survey. *Perm J*. 2016;20(4):15-225. <https://doi.org/10.7812/TPP/15-225>
- Fang MC, Go AS, Prasad PA, Hsu JW, Fan D, Portugal C, et al. Anticoagulant treatment satisfaction with warfarin and direct oral anticoagulants for venous thromboembolism. *J Thromb Thrombolysis*. 2021;52(4):1101-9. <https://doi.org/10.1007/s11239-021-02437-z>
- Cano SJ, Lamping DL, Bamber L, Smith S. The Anti-Clot Treatment Scale (ACTS) in clinical trials: cross-cultural validation in venous thromboembolism patients. *Health Qual Life Outcomes*. 2012;10:120. <https://doi.org/10.1186/1477-7525-10-120>
- Mailhot T, McManus DD, Waring ME, Lessard D, Goldberg R, Bangbade BA, et al. Frailty, cognitive impairment, and anticoagulation among older adults with nonvalvular atrial fibrillation. *J Am Geriatr Soc*. 2020;68(12):2778-86. <https://doi.org/10.1111/jgs.16756>
- Chew LD, Bradley KA, Boyko EJ. Brief questions to identify patients with inadequate health literacy. *Fam Med*. 2004;36(8):588-94.
- Chew LD, Griffin JM, Partin MR, Noorbaloochi S, Grill JP, Snyder A, et al. Validation of screening questions for limited health literacy in a large VA outpatient population. *J Gen Intern Med*. 2008;23(5):561-6. <https://doi.org/10.1007/s11606-008-0520-5>
- Wallace LS, Rogers ES, Roskos SE, Holiday DB, Weiss BD. Brief report: screening items to identify patients with limited health literacy skills. *J Gen Intern Med*. 2006;21(8):874-7. <https://doi.org/10.1111/j.1525-1497.2006.00532.x>
- Kutner, M., Greenburg, E., Jin, Y., Paulsen, C. The health literacy of America's adults: results from the 2003 National Assessment of Adult Literacy (NECS 2006-483). Washington, D.C.: US Department of Education, National Center for Education Statistics 2006.
- Paasche-Orlow MK, Parker RM, Gazmararian JA, Nielsen-Bohlman LT, Rudd RR. The prevalence of limited health literacy. *J Gen Intern Med*. 2005;20(2):175-84. <https://doi.org/10.1111/j.1525-1497.2005.40245.x>
- White RH. The epidemiology of venous thromboembolism. *Circulation*. 2003;107(23 Suppl 1):I4-8. <https://doi.org/10.1161/01.CIR.0000078468.11849.66>
- Fahrni J, Husmann M, Gretener SB, Keo HH. Assessing the risk of recurrent venous thromboembolism—a practical approach. *Vasc Health Risk Manag*. 2015;11:451-9. <https://doi.org/10.2147/VHRM.S83718>
- Tang EO, Lai CS, Lee KK, Wong RS, Cheng G, Chan TY. Relationship between patients' warfarin knowledge and anticoagulation control. *Ann Pharmacother*. 2003;37(1):34-9. <https://doi.org/10.1345/aph.1A198>
- Kagansky N, Knobler H, Rimon E, Ozer Z, Levy S. Safety of anticoagulation therapy in well-informed older patients. *Arch Intern Med*. 2004;164(18):2044-50. <https://doi.org/10.1001/archinte.164.18.2044>
- Davis NJ, Billett HH, Cohen HW, Arnsten JH. Impact of adherence, knowledge, and quality of life on anticoagulation control. *Ann Pharmacother*. 2005;39(4):632-6. <https://doi.org/10.1345/aph.1E464>
- Fang MC, Machtlinger EL, Wang F, Schillinger D. Health literacy and anticoagulation-related outcomes among patients taking warfarin. *J Gen Intern Med*. 2006;21(8):841-6. <https://doi.org/10.1111/j.1525-1497.2006.00537.x>
- Parikh NS, Parker RM, Nurss JR, Baker DW, Williams MV. Shame and health literacy: the unspoken connection. *Patient Educ Couns*. 1996;27(1):33-9. [https://doi.org/10.1016/0738-3991\(95\)00787-3](https://doi.org/10.1016/0738-3991(95)00787-3)
- Houts PS, Doak CC, Doak LG, Loscalzo MJ. The role of pictures in improving health communication: a review of research on attention, comprehension, recall, and adherence. *Patient Educ Couns*. 2006;61(2):173-90. <https://doi.org/10.1016/j.pec.2005.05.004>
- Johnson JL, Moser L, Garwood CL. Health literacy: a primer for pharmacists. *Am J Health Syst Pharm*. 2013;70(11):949-55. <https://doi.org/10.2146/ajhp120306>
- Zhang NJ, Terry A, McHorney CA. Impact of health literacy on medication adherence: a systematic review and meta-analysis. *Ann Pharmacother*. 2014;48(6):741-51. <https://doi.org/10.1177/1060028014526562>
- Barbosa CD, Balp MM, Kulich K, Germain N, Rofail D. A literature review to explore the link between treatment satisfaction and adherence, compliance, and persistence. *Patient Prefer Adherence*. 2012;6:39-48. <https://doi.org/10.2147/PPA.S24752>
- Cart L, Serzian G, Humbert S, Falvo N, Morel-Aleton M, Bonnet B, et al. Clinical patterns and significance of non-compliance with

- guideline-recommended treatment of acute pulmonary embolism. *Arch Cardiovasc Dis.* 2020;113(1):31-9. <https://doi.org/10.1016/j.acvd.2019.09.009>
41. **Spyropoulos AC, Preblich R, Kwong WJ, Lingohr-Smith M, Lin J.** Is adherence to the American College of Chest Physicians recommended anticoagulation treatment duration associated with different outcomes among patients with venous thromboembolism? *Clin Appl Thromb Hemost.* 2017;23(6):532-41. <https://doi.org/10.1177/1076029616680475>
42. **Platt AB, Localio AR, Brensinger CM, Cruess DG, Christie JD, Gross R, et al.** Can we predict daily adherence to warfarin?: results from the International Normalized Ratio Adherence and Genetics (IN-RANGE) study. *Chest.* 2010;137(4):883-9. <https://doi.org/10.1378/chest.09-0039>
43. **Ng DL, Gan GG, Chai CS, Chee KH, Tan KL, Tan SB, et al.** Comparing quality of life and treatment satisfaction between patients on warfarin and direct oral anticoagulants: a cross-sectional study. *Patient Prefer Adherence.* 2019;13:1363-73. <https://doi.org/10.2147/PPA.S204246>
44. **Packard A, Delate T, Martinez K, Clark NP.** Adherence to and persistence with direct oral anticoagulant therapy among patients with new onset venous thromboembolism receiving extended anticoagulant therapy and followed by a centralized anticoagulation service. *Thromb Res.* 2020;193:40-4. <https://doi.org/10.1016/j.thromres.2020.05.036>

Publisher's Note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

Springer Nature or its licensor (e.g. a society or other partner) holds exclusive rights to this article under a publishing agreement with the author(s) or other rightsholder(s); author self-archiving of the accepted manuscript version of this article is solely governed by the terms of such publishing agreement and applicable law.