Patient Satisfaction With Venous Thromboembolism Treatment

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Abstract

Venous thromboembolism (VTE) represents a major health-care problem. Understanding patient satisfaction with VTE care is an important health-care goal. A national online survey was administered to adults who had experienced a recent VTE event. The survey assessed patient satisfaction by: (1) satisfaction with VTE care provider; (2) likelihood to recommend VTE provider; and (3) satisfaction with communication between VTE care providers. Each question was correlated with patient demographics, patient care harms (ie, misdiagnosis, wrong treatment), patient beliefs concerning outcomes, and type of anticoagulant therapy. Respondents (907) were 52.4 + 14.4 years, predominantly Caucasian, mostly women, and generally had health insurance. Most respondents were satisfied with VTE care providers, likely to recommend their VTE provider, and satisfied with communication between providers. Dissatisfaction was strongly associated with treatment mistakes, a wrong diagnosis or treatment, or delayed treatment. A national sample of VTE patients were generally satisfied with VTE care experiences. The VTE care dissatisfaction was strongly associated with perceived mistakes in VTE care. Interventions aimed at reducing, acknowledging, and communicating errors could be studied to improve VTE care satisfaction.

Keywords

anticoagulants, venous thromboembolism, patient satisfaction, treatment errors, deep venous thrombosis, pulmonary embolism

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Introduction

Venous thromboembolism (VTE) is a common disease of both young and older patients and is associated with reduced mortality, a high rate of recurrence, and substantial health-care costs.¹ Thirty percent of patients with VTE have a recurrence within 10 years. Due to the high recurrence rate, VTE has a major impact on the patients' quality of life as concerns are raised about disease progression, reoccurrence, and the need for life-long anticoagulant therapy in some cases.² Consequently, patients who have been diagnosed with VTE often suffer from emotional distress.² Patients who report experiencing higher levels of anxiety and emotional distress are at greater risk of recurrent VTE.3 Treatment of VTE with anticoagulant medications is commonly associated with bleeding and bruising, which may also increase emotional distress due to patients worrying about these events occuring. 4 Emotional distress is often accompanied by general dissatisfaction and pessimism, which can result in decreased patient satisfaction.^{5,6}

Little is known about what specific factors are associated with overall patient VTE care satisfaction. Patient satisfaction

is multifactorial and is associated with multiple sociodemographic factors including sex, age, racial identity, employment status, educational level, and insurance status. 5,7-9 It has been shown that increased patient satisfaction will generally lead to overall improved patient outcomes, including decreased hospital readmission rates, increased patient therapy compliance, 5,10,11 and better ability to recall physician recommendations.^{5,12} The purpose of this study is to explore the specific impact of various factors on levels of patient satisfaction with VTE care and assess

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how patient satisfaction is related to patient beliefs and self-reported harms.

Methods

Sample and Procedure

This study was approved by the University of Utah's institutional review board before initiating data collection. All participants provided informed consent prior to commencing the survey. The sample was comprised of patients recruited by an independent contract research organization (Hall & Partners, New York, New York) from a nationally representative panel of consumers who preenrolled to participate in research studies (Research Now; Research Now Group, Inc, New York, New York). Between May 10, 2016, and July 10, 2016, eligible patients self-completed online surveys on a first-come basis until the predetermined sample size of approximately 1000 was achieved. Patients accessed the survey electronically through a link in an invitation e-mail and were offered an industry standard honorarium for completing the survey. Patients were screened to be those aged 18 years or older who experienced at least 1 VTE event in the past 2 years. Patients diagnosed with cancer within the past 2 years were excluded.

Survey

Baseline characteristics. Patients indicated their sex, age in years, and their self-identification of race and ethnicity. Patients also responded to whether they had health insurance currently, whether their residence was located in a rural or urban community, and what their total household income was before taxes. Patients indicated whether their most recent VTE was deep vein thrombosis (DVT), pulmonary embolism (PE), or both, whether their most recent VTE event occurred within the past month, and whether the most recent VTE event occurred within 30 days of a surgical procedure. Patients indicated which anticoagulant medications they had been prescribed for their most recent VTE event, selecting single or multiple agents from the following: warfarin, direct oral anticoagulants (dabigatran, rivaroxaban, apixaban, edoxaban), injectables (low-molecular-weight heparin, unfractionated heparin), and/or aspirin. Patients could also indicate if no anticoagulant therapy was prescribed.

Health-care use and satisfaction correlates. Patients indicated their level of comorbid health conditions by selecting from a list of conditions diagnosed by their doctors in the past 2 years. Patients were asked how often they typically visit a primary health-care provider in the past 12 months. Barriers to health-care service access were assessed by asking, on a 10-point rating scale (from 1 = "not at all difficult" to 10 = "extremely difficult"), how difficult it was to meet costs related to their VTE care and their VTE prescription medications and whether transportation issues made it difficult to get their VTE care. On another 10-point Likert scale (from 1 = "not at all needed" to 10 = "extremely needed"), patients indicated the degree to which they needed the support of others at home to get their

VTE care. The difficulty or further need of support were then defined as the score of 8 or above on the Likert scale.

Patients indicated their overall level of satisfaction with the provider who provided the majority of their VTE care. Satisfaction with VTE care for their most recent VTE event was assessed across multiple health-care settings including hospital, primary health-care provider's office, specialty health-care provider's office, anticoagulation clinic, and home. Patients also indicated their level of satisfaction with communication between the providers responsible for their VTE care. Each of these was scored on a Likert scale from 1 = "very dissatisfied," 2 = "somewhat dissatisfied," 3 = "neither dissatisfied nor satisfied," 4 = "somewhat satisfied," and 5 = "very satisfied." Satisfaction was defined as scores of 4 or 5 on this scale. On the same scale, patients indicated their satisfaction with the VTE education provided by their health-care providers in conversation, through printed materials (eg, brochures, booklets, etc), via online resources recommended by their health-care provider (eg, medical websites, medication websites, etc), and through patient support groups. Finally, patients were asked to indicate how likely they would be to recommend the health-care provider who was primarily responsible for the majority of their care to friends or relatives if they also experienced a VTE event on a scale from 1 to 10, where 1 means "not at all likely" and 10 means "extremely likely." Responses of 8 or higher on the Likert scale defined those who would recommend their VTE provider to others. An open text response field allowed patients to explain why they chose the rating for recommending their provider to others.

Emotional harms. The Hospital Anxiety and Depression Scale (HADS) was used to assess the level of current VTE-related anxiety and depression experienced by patients. 13 The HADS scale comprises two 7-item subscales for anxiety and depression, each with high previously reported internal consistency. Each item is scored on a 4-point Likert scale of 0 = "not at all," 1 = "from time to time, occasionally," 2 = "a lot of time," and 3 = "most of the time." Patients were asked the following questions regarding mistakes in VTE care: "Has a doctor EVER made a mistake in your VTE care (Yes/No)?"; "Has a doctor EVER made a wrong diagnosis or misdiagnosed you in relation to a VTE event (Yes/No)?"; and "Has a doctor EVER given you the wrong medical treatment or delayed treatment for your VTE care?" Patients were also asked to indicate whether any of these mistakes in care had happened within the previous 12 months (Yes/No).

Psychosocial correlates. Quality-of-life scores were collected using the Optum Health Survey Short-Form 12 (SF-12), a validated widely used quality-of-life assessment instrument. The SF-12 is composed of Physical Health Component Summary and Mental Health Component Summary scores. Patients indicated their degree of perceived control over health using the Multidimensional Health Locus of Control (MHLC) Scales-Form C.¹⁴ This 18-item instrument is designed to be adapted for any medical condition. For this study, items were reworded

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to reflect VTE (eg, "Whatever goes wrong with my VTE is my own fault"). The MHLC scales comprise 4 subscales with established reliability and validity metrics: internality, chance, doctors, and other people. 14-16 People who score high on the internality scale believe their own health behaviors determine their health status, those who score high on the chance subscale believe their health status lies outside their control, the doctors subscale indicates belief that health status lies with doctors, and the other people subscale indicates that people other than the patient influence health status. 15

Statistical Analysis

Descriptive statistics examined the frequency or mean and standard deviation (SD) of categorical and continuous variables, respectively. Independent variables were correlated with VTE care satisfaction outcomes to examine the strength and direction of associations. Relevant variables where statistically significant differences existed between patients who did and did not express satisfaction with VTE care from the bivariate analyses were included in a multivariable linear regression model predicting the likelihood of being dissatisfied with recent VTE care, not recommending VTE provider to others, and dissatisfaction with communication between VTE providers. All data were analyzed with SAS v9.4 (Cary, North Carolina) with significance set at a *P* value of <.05.

Results

Of the eligible sample, a total of 971 patients entered and completed the full survey. After the data set was cleaned to remove those patients giving nonsensical data (ie, not providing variation in answers, completing the survey in unrealistically short time, giving manifestly inconsistent responses), there was a total of 907 (93.4%) surveys available for analysis. The demographics of the final sample are summarized in Table 1. Overall, the respondents were middle-aged (52.4, SD: 14.4) years), mostly female (56.7%), the majority Caucasian (86.6%), lived mainly in urban communities (82.7%), nearly all reported they had health insurance (97.4%), and most had annual income >\$25 000 (84.2\%). Most respondents reported multiple comorbid conditions, with the most commonly reported being a prior history of DVT (84.8%) or PE (33.7%), high blood pressure (45.6%), depression (28.5%), heart disease (27.5%), and anxiety (26.7%). The most recent VTE event reported was DVT (63.8%) and PE (18.1%) and 18.1% experienced both DVT and PE. There were no statistically significant differences between respondents who were and were not satisfied with their overall VTE care in terms of general demographics, comorbid conditions, time since most recent VTE, VTE type, frequency of primary care provider visits, and anticoagulant therapy type (Table 1).

Most patients (87.2%) indicated at least some degree of satisfaction with their most recent VTE care experience. The mean score aligned with a ranking of being moderately satisfied with the care provided by the health-care provider primarily

responsible for their VTE care (4.30, SD: 0.97 on a 5-point Likert scale). Overall, 69.9% of patients indicated that they would recommend (score ≥ 8 on a 10-point Likert scale) the provider primarily responsible for their VTE care to friends or family members (8.09, SD: 2.30 on a 10-point Likert scale). Patients also indicated that they were moderately satisfied with the communication between their VTE health-care providers regarding their VTE care (81.8% ≥ 4 ; 4.20, SD: 1.03 on a 5-point Likert scale).

The proportion of patients expressing satisfaction with VTE care received in the hospital (687/817, 84.1%), primary care provider's office (726/856, 84.8%), specialty provider's office (639/744, 85.9%), and at home (648/773, 83.8%) was similar and higher than for care received at "thrombosis services" (224/390, 74.9%). Conversely, proportions of dissatisfaction ranged from 25.1% (thrombosis services) to 14.1% (specialty provider's offices). The proportion of patients expressing satisfaction with VTE care educational material provided by conversation was 692 of 858 (80.7%), through printed material 603 of 795 (75.8%), through online material 537 of 693 (77.5%), and through patient support groups 229 of 362 (63.3%), respectively.

Patients who were satisfied with their overall VTE care were more likely to recommend the provider primarily responsible for their VTE care to others (78.3% vs 12.9%, P < .001) and were also more likely to be satisfied with communication between their VTE providers (90.0% vs 25.9%, P < .001) than those who were dissatisfied with their VTE care (Table 2).

Patients expressing satisfaction with VTE care with the provider primarily responsible for providing VTE care were less likely to have below average quality of life as measured by the SF-12 Physical Component Score. A similar trend was seen in the SF-12 Mental Component Score, but this difference was not statistically significant (Table 2). Patients who believed that their own health behaviors or their doctor's actions determine their VTE health status as measured by MHLC internal and doctors' scores were more likely to express overall satisfaction with their VTE care. Patients reporting abnormal levels of VTE-related anxiety or depression as measured by HADS scores were more likely to express overall dissatisfaction with VTE care.

Table 3 shows regression modeling outcomes for the satisfaction with the provider primarily responsible for providing VTE care, likeliness to recommend this provider, and communication between VTE provider questions, respectively. Multivariable regression modeling showed that mistakes in VTE care, a wrong diagnosis or treatment resulting in need to change doctors, and the need to change providers due to mistakes in VTE care were strongly associated with dissatisfaction. Mistakes in VTE care were associated with 3-fold increased odds of dissatisfaction in overall VTE care and dissatisfaction with the communication between VTE providers and 2-fold increased odds of being less likely to recommend the provider primary responsible for VTE care to others. Having to change providers due to mistakes in care similarly doubled the odds of dissatisfaction with overall VTE care and communication between VTE providers. Other associations such as MHLC internal and doctors scores, HADS depression

Table 1. Patient Baseline Characteristics Categorized by Overall Satisfaction With VTE Care.

Characteristic	Total (N = 907)		Dissatisfied With Most Recent VTE Care (N = 116, 12.8%)		Satisfied With Most Recent VTE Care (N $=$ 791, 87.2%)		
	N, Mean	SD, %	N, Mean	SD, %	N, Mean	SD, %	P Value
Female	514	56.7	68	58.6	446	56.4%	.65
Age in years, mean	52. 4	14.4	50.9	13.5	52.6	14.5	.22
Race							
Caucasian	804	88.6	105	90.5	699	88.4	.50
Other	103	11.4	11	9.5	92	11.6	
Ethnicity							
, Hispanic	96	10.6	13	11.21	83	10.5	.82
Community residence							
Rural	157	17.3	19	16.4	138	17.5	.78
Urban	750	82.7	97	83.6	653	82.6	
Insurance status							
Insured	883	97.4	110	94.8	773	97.7	.07
Annual income							.72
High (≥\$100 000)	241	26.6	27	26.6	214	27.1	
Medium (\$50 000-\$99 999)	329	36.3	45	36.3	284	35.9	
Low (\$25 000-\$49 999)	193	21.3	23	21.3	170	21.5	
Very low (<\$25 000)	144	15.8	21	15.9	123	15.6	
Comorbidities ^b		13.0	2.	13.7	123	13.0	.33
Anxiety	242	26.7	41	35.3	201	25.4	.55
DVT	769	84.8	101	87.I	668	84.5	
Depression	258	28.5	37	31.9	221	27.9	
Diabetes	156	17.2	19	16.4	137	17.3	
Heart disease	249	27.5	35	30.2	214	27.I	
	414	45.6	47	40.5	367	46.4	
Hypertension PE	306	33.7	41	35.4	265	33.5	
Stroke	77	8.5	16	13.8	61	7.7%	21
Time since most recent VTE	174	10.2	7		70	0.0	.31
≤30 days	174	19.2	7	6.0	70 72.1	8.9	
>30 days	733	80.8	109	94.0	721	91.2	0.7
Most recent VTE type	F.70	42.0	47	57.0	510		.07
DVT	579	63.8	67	57.8	512	64.7	
PE	164	18.1	19	16.4	145	18.3	
Both	164	18.1	30	25.9	134	16.9	
Frequency of PCP visits			• •				.50
Monthly	158	17.4	24	20.7	134	16.9	
Every 2 to 5 months	365	40.2	46	39.7	319	40.3	
Every 6 months	255	28.1	27	23.3	228	28.8	
≤I/year	129	14.2	19	16.4	110	13.9	
Anticoagulant therapy type							.28
Injectable anticoagulants	35	3.9	4	3.4	31	3.9	
Warfarin	351	38.7	42	36.2	309	39.1	
DOACs	237	26.1	31	26.7	206	26.0	
Switch/warfarin and DOACs	121	13.3	13	11.2	108	13.7	
Switch between DOACs	41	4.5	4	3.4	37	4.7	
Aspirin	79	8.7	11	9.5	68	8.6	
No Therapy	43	4.7	11	9.5	32	4.0	

Abbreviations: DOAC, direct oral anticoagulant; DVT, deep vein thrombosis; PCP, primary care provider; PE, pulmonary embolism; VTE, venous thromboembolism.

or SF-12 mental component scores, or perceived barriers with transportation for VTE care were only modestly associated with dissatisfaction and likelihood of recommending the patient's VTE provider to others.

Discussion

Our study shows a majority of patients who had suffered a VTE event in the past 2 years and completed a national online survey expressed at least moderate levels of satisfaction with their

^aDefined as score of I to 3 on a 5-point Likert scale pertaining to satisfaction with provider who was primarily responsible for VTE care.

^bPatients could select more than one comorbidity.

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Table 2. Comparison of Outcome Measures for Patients With Recent VTE Categorized by Overall Satisfaction With VTE Care.

	Dissatisfied ^a With Most F	Recent VTE Care ($N = 116$)	Satisfied With Most Recent VTE Care (N = 791)		
Characteristic	n	%	n	%	P Value
Recommend VTE provider t	o others				
Likely	15	12.9	619	78.3	<.001
Communication between V7	E care providers				
Satisfied	. 30	25.9	712	90.0	<.001
SF-12 Health Survey (Quality	of Life) score <50 (below	v average)			
Mental component score	75	64.7	439	55.5	.08
Physical component score	99	85.3	590	74.6	.02
Multidimensional Health Loc	us of Control (MHLC) sco	ore in top quartile			
Internal score	18 [°]	15.5	204	25.8	.02
Chance score	25	21.6	201	25.4	.43
Doctors score	25	21.6	328	41.5	<.01
Other people score	45	38.8	272	34.4	.41
Hospital Anxiety and Depres	ssion Scale (HADS) score	II+ (abnormal)			
Anxiety	`45	` 38.́8	179	22.6	<.01
Depression	30	25.9	75	9.5	<.01

Abbreviations: SF-12, short form-12 question survey; VTE, venous thromboembolism.

Table 3. Bivariate and Multivariate Regression Analysis.

	Bivariate Association, Odds Ratio ^a (95% Confidence Interval)	Multivariate Association, Adjusted Odds Ratio ^a (95% Confidence Interval)
Overall dissatisfaction with VTE care		
MHLC internal score	1.07 (1.04-1.10)	1.04 (1.00-1.08)
MHLC doctors score	1.30 (1.20-1.40)	1.23 (1.13-1.35)
HADS depression	1.12 (1.08-1.18)	1.08 (1.02-1.14)
Meet transportation issues	1.07 (1.008-1.14)	1.42 (0.88-2.29)
Mistake in VTE care	2.78 (1.54-5.26)	3.27 (1.93-5.53)
Wrong VTE diagnosis or wrong treatment resulting in changing providers	2.44 (1.33-4.35)	2.72 (1.57-4.71)
Not likely to recommend VTE provider to others		
MHLC doctors score	1.41 (1.32-1.51)	1.33 (1.24-1.43)
HADS depression	0.88 (0.85-0.91)	0.94 (0.90-0.98)
Meet transportation issues	1.08 (1.01-1.18)	1.10 (1.03-1.16)
Mistake in VTE care	2.13 (1.33-3.85)	2.38 (1.47-4.00)
Dissatisfaction with communication between VTE providers	5	
SF-12 Mental Component Score	1.04 (1.02-1.05)	1.03 (1.01-1.05)
MHLC internal score	1.07 (1.04-1.10)	1.04 (1.00-1.07)
MHLC doctors score	1.36 (1.26-1.46)	1.31 (1.21-1.42)
Mistake in VTE care	2.70 (1.54-4.55)	2.86 (1.75-4.69)
Wrong VTE diagnosis or wrong treatment resulting in changing providers	1.85 (1.05-3.23)	2.06 (1.22-3.46)

Abbreviations: HADS, Hospital Anxiety and Depression Scale; MHLC, Multidimensional Health Locus of Control; SF-12, short form-12 question survey; VTE, venous thromboembolism.

overall VTE care experience and the communication between VTE care providers. Further, most patients would recommend the provider primarily responsible for their VTE care to others. Satisfaction with VTE care was associated with improved quality of life, a perception of greater self-control over VTE healthcare status, and less depression and anxiety. Patients who reported dissatisfaction with their VTE care were less likely

to recommend their VTE provider and were less likely to be satisfied with the communication between their VTE providers, especially when they perceived mistakes in VTE care and/or a wrong VTE diagnosis or treatment had occurred.

US health-care consumers are largely positive about the quality of health care they receive. Approximately 77% of Americans said the health care they received was excellent or good in

^aDefined as score of I to 3 on a 5-point Likert scale pertaining to satisfaction with provider who was primarily responsible for VTE care.

^aOdds ratios or adjusted odds ratios >1.0 indicate dissatisfaction with VTE care.

Gallop poll from November 2017.¹⁷ Patient satisfaction affects clinical outcomes including timely, efficient, and patient-centered delivery of quality health care.¹⁸ Patient satisfaction can therefore be a proxy for health-care success across different practices. Our study of satisfaction with VTE care showed similar rates of patient satisfaction and also that 1 in 5 patients expresses some level of dissatisfaction with VTE care.

Our results suggest that patient perceptions of mistakes in VTE care or poor communication between providers during the VTE care process appears to be a driver of poor satisfaction with VTE care. Specific comments provided by patients in "open-text" survey responses provide context to the adjusted odds ratio findings from multivariate regression analysis that indicated a strong association with errors and/or mistakes in care and dissatisfaction. Examples include the following quotes: "The doctor totally missed all the details I gave her of my symptoms. All the symptoms were there. Incompetent Doctor." "He had my blood thinned to the point that I was bleeding internally and had to have blood transfusions and admitted to the area hospital. He did NO patient education for the blood thinners." "I had a saddle embolism and the primary care physician gave me an inhaler and sent me home." Interventions such as the use of diagnostic algorithms, special care around transitions from one site of care to another, and a structured process for monitoring anticoagulant therapy may help to avoid these types of mistakes and thus improve overall satisfaction with VTE care.

The diagnosis and treatment of VTE includes complexity that may contribute to risk of missed diagnosis and perceived medical errors. Complexity may be exacerbated by a lack of a coordinated data management and communication among providers through many different electronic medical record platforms, although adoption of health information technology is improving rapidly. 19,20 Packed provider visit schedules and short appointment times are known barriers interfering with the provider-patient relationship and may reduce patient connectivity and satisfaction, thereby contributing to perceptions of poor communication and mistakes in care. 21 In addition to misdiagnosis, this can lead to unnecessary referrals, overtreatment, and patient confusion regarding their condition including whether to initiate, adjust, continue, or discontinue care, often without provider input. Health illiteracy, affecting as many as 50% of the population, should also be considered.²² Care complexity reflects how important the provider-patient interaction is to patient satisfaction in the provision of VTE care.²³

Our survey was designed to capture patient experiences as they transitioned between various sites of care during their VTE treatment. Overall, the majority of patients were satisfied with the VTE care they received in the hospital, in physician's offices, and at home. Although 7 of 10 patients expressed satisfaction with the care they received from "thrombosis services," this proportion was lower than for other care sites. The number of patients who indicated they had received care in thrombosis services was lower than other care sites and perhaps there was confusion about the meaning of this term.

Overall, a high proportion of patients expressed satisfaction with the education materials they received from their VTE care providers, with the exception of education received through patient support groups. Comparatively fewer patients indicated that they had participated in patient support groups than other types of education.

The present study has limitations including the online nature of the survey which may have resulted in the elderly patients without computer access and lower income patients being underrepresented in the study. We were not able to assess interventions aimed at improving VTE care satisfaction due to the cross-sectional nature of our survey. We relied primarily on self-reported metrics which may be subject to various forms of bias. However, we collected data from a large national population which increases the generalizability of our results. We also used validated outcome measures which increases the reliability of the findings reported in our study.

Conclusion and Relevance

This study shows that most patients with a recent VTE episode who responded to an online survey were at least moderately satisfied with the care they received from the provider primarily responsible for their VTE care and are likely to recommend this provider to others. Importantly, VTE care dissatisfaction was strongly associated with perceived mistakes in care. Therefore, interventions aimed at reducing diagnostic or treatment errors are important to avoid erosion in VTE care satisfaction. We hope the results of our study will provide helpful information to other investigators interested in designing studies that will assess the outcomes of interventions aimed at improving patient satisfaction. For example, as a belief that doctors are primarily responsible for VTE outcomes was associated with dissatisfaction with VTE care, the impact of interventions aimed at empowering patients such as patient education programs or patient support groups could be assessed in future studies. Other studies could assess the impact of implementing a structured communication plan for acknowledging and disclosing mistakes in VTE care on patient satisfaction.²⁴

Authors' Note

All authors fully contributed to the content of this manuscript, including meeting the 4 criteria of the Internal Committee of Medical Journal Editors. All authors had full access to all of the data in the study and take full responsibility for the integrity of the work and accuracy of the data analysis, from inception to published article.

Declaration of Conflicting Interests

The author(s) declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: Dr Feehan has consulted with Pfizer previously.

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