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Leiden
The Netherlands

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Korlaar, I.M. van

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Chapter 6

Using the Common-Sense Model to predict risk perception and disease-related worry in individuals at increased risk for venous thrombosis

I.M. van Korlaar, L.D. Cameron, C.Y. Vossen, F.R. Rosendaal,
F.J.M. van der Meer, & A.A. Kaptein

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Abstract

This study applied the Common-Sense Model (CSM) to predict risk perception and disease-related worry in 174 individuals with a genetic predisposition to venous thrombosis (thrombophilia). Participants completed an adapted version of the Illness Perception Questionnaire-revised (IPQ-R) and measures assessing risk perception and worry. Regression analyses revealed that illness perceptions were only modest predictors of risk perception but better predictors of worry, suggesting that illness perceptions are more linked with affect after genetic screening rather than cognitive appraisals of disease risk. Further research should refine the IPQ-R in populations at risk of a disease and examine the value of the CSM in explaining the relationship between risk perception, worry, and health behavior.

Introduction

Perceived risk of disease is the expectancy of an individual of getting a specific disease at some point in his or her life, and its role as a determinant of health behavior is well established. In the area of cancer screening, risk perceptions have been found to be positively associated with screening intentions and protective behavior such as breast self-examinations (1;2). Inaccurate perceptions of risk are commonly held by individuals at risk of a disease, and they tend to persist even after genetic counseling (3). These inaccurate perceptions of disease risk could have a negative effect on well-being and preventive behavior. A growing body of research indicates that disease-related worry also plays a motivational role in promoting health behavior, and that its associations with behavior are sometimes even stronger than the associations of risk perception (4-7). Although risk perception and disease-related worry tend to be correlated (4), it appears that they can have distinctive influences on health behavior.

Relatively little research has examined how individuals formulate their appraisals of disease risk and what factors influence their disease-related worry. Perceptions of health risk are fundamentally based on perceptions of the target illness, and so our understanding of the construction of risk perceptions can be informed by the theoretical understanding of illness representations. In this light, the Common-Sense Model of illness representation and self-regulation (CSM) can be useful in understanding risk perceptions and worry about disease in individuals at a genetic risk for a disease (8-11). The CSM can provide a theoretical framework in understanding the meaning of risk by focusing on the health threat that individuals perceive they are at risk of experiencing (12;13). The model describes a system with two parallel pathways of self-regulatory processes that operate when a patient confronts a health threat. Components of the first pathway include the cognitive representation of an illness, which includes five representational at-

tributes: the label and symptoms that individuals associate with the illness (identity), beliefs about the etiology (cause), expected outcomes (consequences), beliefs about the duration (timeline) and the expected controllability (cure/control) of the illness (11;14). The second pathway of the model involves the regulation of emotional reactions to a health threat, such as worry and distress; these emotions are shaped by the representational attributes. Perceived risk and worry about health threats are reflected in these two pathways, respectively. The information represented in each of the domains of illness representations may influence perceptions of disease risk and worry about the disease (12).

The CSM has been applied primarily in studies aimed at understanding psychological responses in patients who are physically ill. Studies investigating the influence of illness perceptions on outcome in patients with a chronic illness have provided support for the hypothesis that a strong illness identity (the attribution of many symptoms to an illness), as well as beliefs in a long duration and serious consequences have a negative effect on the well being of patients (15;16). Yet it is likely that illness perceptions are also important predictors of responses to health threats in healthy individuals, such as those with a genetic predisposition to an illness (17). In families with a history of a certain disease, it is likely that genetically predisposed but asymptomatic family members have witnessed episodes of the disease in their close relatives. These experiences, together with the information received from medical caregivers and gathered by themselves (e.g., through the Internet), may provide the basis for perceptions about the disease which, in turn, guide their risk perceptions and worry about this health threat.

Only few empirical studies have applied the CSM to study the impact of illness perceptions in a population at an increased risk of a disease. A study by Rees and colleagues, assessed the relationship between illness perceptions and distress in women at an increased risk of breast cancer and found a modest relationship between cancer worry and the subscales assessing identity, acute/chronic timeline, and consequences beliefs (18). Kelly and colleagues used the Common-Sense Model in a qualitative study to understand cancer risk perceptions in individuals testing for BRCA1/2 mutations (19). The findings suggested that individuals based their risk perceptions on beliefs regarding the causes of cancer (such as a family history of breast cancer), control or cure of cancer through health behaviors or surgery, and the timeline for developing cancer. In this paper, we used the CSM as the theoretical framework for an assessment of risk perceptions and thrombosis-related worry in a population of individuals with a genetic predisposition to venous thrombosis. This population has received little attention in research on risk perceptions and genetic testing.

In the past several years, several genetic factors that predispose to venous thrombosis have been identified (20-23). Venous thrombosis is a multi-causal disease that is characterized by the formation of a blood clot (thrombus) in a vein, which blocks the blood flow from the affected body part. Symptoms of a venous thrombosis in the deep veins of the legs include pain, swelling, redness and tenderness of the skin. The major

complication, pulmonary embolism, which may be life-threatening, happens when a part of the clot embolises to the lungs. Chronic impairment of the venous outflow of the leg, the postthrombotic syndrome, may cause severe disability. The annual incidence of diagnosed venous thrombosis, including pulmonary embolism, is 1-3 in 1000 individuals (24). Quality of life in individuals with venous thrombosis is impaired relative to that of the general population, especially in the presence of the postthrombotic syndrome. This impairment encompasses physical, social and psychological domains of quality of life (25-27).

Thrombophilia is an increased tendency to develop venous thrombosis, often due to a genetic defect. Among the genetic risk factors that have been discovered so far are factor V Leiden, protein C, protein S, and antithrombin deficiency (20-23;28). Individuals from families with inherited thrombophilia have a 10-20 times increased risk of venous thrombosis compared with a normal population (relative risk 15.7, 95% CI 9.2-26.8) (29). A combination of defects is associated with the greatest risk of venous thrombosis. For the single defects, the lowest risk is associated with Factor V Leiden and the highest risk with antithrombin deficiency (29-31). Although it is possible to treat individuals at a risk of venous thrombosis with prophylactic anticoagulant treatment, this treatment itself encompasses a risk of complications such as bleeding (32;33). Therefore, debate continues about whether widespread thrombophilia testing is beneficial in terms of improved prevention and management of thrombosis, as the benefit of treatment should be weighed against the risk of severe haemorrhage (34;35). Individuals with thrombophilia face uncertainty regarding if and when venous thrombosis will develop, and if and how they can prevent this.

Literature about the possible emotional consequences of genetic testing for thrombophilia is scarce and emotional consequences have not been taken into account in the debate on the usefulness of thrombophilia screening. As in similar conditions such as hypercholesterolemia, it is important to pay attention to the psychological impact of testing for thrombophilia (36). To our knowledge only three publications have evaluated the social and psychological impact of awareness of carriership of thrombophilia (37-39). These studies indicated that individuals who tested positive for thrombophilia were faced with increased worry about developing thrombosis, stigmatization, and problems with insurance eligibility.

The primary objectives of the current study were to examine the representations of venous thrombosis developed by thrombophilic individuals, and to assess the associations of these representations with perceptions of the likelihood of getting thrombosis and thrombosis worry. We predicted that past experience of venous thrombosis would be associated with perceptions of greater likelihood of experiencing venous thrombosis in the future. Furthermore, it was predicted that older individuals without a personal history of venous thrombosis would perceive venous thrombosis to be less likely than younger individuals, based on the reasoning that if it was likely to occur, then they would

have experienced it by this point in their lives. Both of these associations would suggest 'logical' appraisals of perceived likelihood. Yet likelihood perceptions can also be influenced by 'nonrational' influences. Specifically, we expect that the more one has strong consequences beliefs (which are more likely than weak consequence beliefs to involve vivid, graphic, easily imagined scenarios of suffering) and high coherence beliefs (i.e., a clear, developed, coherent representation of the illness), the greater the perceived likelihood of venous thrombosis. These effects would reflect the use of the availability and simulation heuristics (40;41). Thus, we hypothesized that 'consequences' and 'coherence' beliefs would have strong associations with risk perception. Furthermore, theoretically, all of the IPQ-R subscales should be associated with disease-related worry for people who know they are at a genetic risk for a disease (12). In line with the findings of Rees et al. (18), we expect that participants with strong 'identity' and 'consequences' beliefs (those who perceive venous thrombosis as having more symptoms and more serious consequences) will have higher levels of thrombosis worry.

Method

Participants and procedure

Participants in this study were adult thrombophilic individuals who were enrolled in the European Cohort on Thrombophilia (EPCOT) study in the Netherlands between 1994 and 1997 and followed until 2001 (42;43). Included were all registered probands (first of a family in whom thrombophilia was detected) with a deficiency of antithrombin, protein C, protein S or factor V Leiden, and their registered relatives with thrombophilia. Participants in this study had to be over 18 years old and capable of completing a questionnaire. Data were collected in 2004 by mailed questionnaires. Non-responders received a reminder questionnaire about 2 months after the initial questionnaires were sent out. All participants signed an informed consent form to use previously collected medical data for this study.

Measures

Demographic and illness related variables. Demographic and illness-related variables of all participants were collected and included age, gender, thrombosis history (dates, location of the thrombosis), and details about the type of thrombophilia (protein C deficiency, protein S deficiency, antithrombin deficiency, Factor V Leiden or a combination of Factor V Leiden and other defects).

Illness perceptions. To measure illness perceptions, the revised version of the Illness Perception Questionnaire (IPQ-R) was used, which is a measure based on the CSM (44). The

original Illness Perception Questionnaire (IPQ) was designed to assess the five attributes of illness representations: identity, timeline, consequences, control and cause (45). In the revised version, a subscale was added to assess emotional representations, such as anxiety and anger, generated by an illness. The IPQ-R also incorporates a subscale called 'illness coherence'. This subscale was added to assess the extent to which the illness makes sense to the patient. Furthermore, it includes a measure of how much one believes an illness fluctuates or comes and goes over time ('cyclical timeline'), and it has separated the 'cure/control' subscale into 'personal control' and 'treatment control' subscales.

The questionnaire was adapted for use in a population with thrombophilia so that both participants *with* a history of thrombosis and participants *without* a history of thrombosis could complete the same set of questions. The identity scale consisted of 14 general symptoms and asked participants to state whether they believe this symptom is related to venous thrombosis; scores reflect the number of illness-related symptoms. The items for the acute/chronic timeline, cyclical timeline, consequences, personal control, treatment control, illness coherence and emotional representations subscales were rated on a 5-point Likert type scale ranging from *strongly disagree* to *strongly agree*. All items were adapted for use in a population that is genetically predisposed to venous thrombosis, but does not necessarily have a personal experience with the illness. For instance 'My illness will last a short time' was replaced by 'Venous thrombosis lasts a short time'. The total number of items in this section is 37. Scores were the mean rating for each subscale. The last section presented the causal dimension, consisting of 24 items rated on the same 5-point Likert scale ranging from *strongly disagree* to *strongly agree*. Six causes that are specific risk factors for venous thrombosis (such as the use of the oral contraceptives and prolonged bed-rest) were added to the original 18 causes from the IPQ-R. An open-ended question asked individuals to list any other causes that are important to them.

Risk perception. Perceived risk of venous thrombosis was assessed with two items that were adapted from Cameron & Diefenbach (4) ($r=.74$): 1. How likely do you think it is that, at some point in your life, you will get thrombosis? 2. How vulnerable do you think you are to getting thrombosis at some point in your life? Each item was rated on a 7 point Likert scale ranging from 1 (*not at all*) to 7 (*almost certain or extremely*). To calculate a score for risk perception, ratings on both items were added (range 2-14).

Thrombosis worry. Worry about venous thrombosis was assessed with two items ($r=.90$) (4): 1. To what extent are you worried about getting thrombosis? 2. To what extent are you concerned about getting thrombosis? Each item was rated on a 7 point Likert scale ranging from 1 (*not at all*) to 7 (*extremely*). These ratings were summed to generate a thrombosis-related worry score (range 2-14).

Statistical analysis

All data were entered and analyzed using SPSS 11.5. Means and standard deviations were calculated for all measures. Internal consistency of the subscales of the IPQ-R was established by calculating Cronbach's alpha coefficients. To compare differences in scores between participants with and without a history of venous thrombosis, *t* tests and 95% confidence intervals were used. To detect differences in scores between participants with different types of thrombophilia analyses of covariance (ANCOVA) were used. Pearson correlations were calculated to detect relationships between the subscales of the IPQ-R, thrombosis worry and perceived risk. To assess the independent associations of the illness perceptions with perceived risk and thrombosis worry scores, regression analyses were performed. In these analyses, demographic and disease-related variables (age, thrombosis-history, and type of thrombophilia) were entered in step 1 and illness perceptions were entered in step 2.

Results

Demographic variables

Questionnaires were sent to 251 individuals. A total of 196 out of 251 individuals (78%) returned the questionnaire. Twelve questionnaires were incomplete, and were therefore not included in the analyses. Furthermore, 10 participants had suffered only from superficial thrombophlebitis. Since this group will potentially have different perceptions of venous thrombosis, but is too small for quantitative analyses, we removed these participants from the present analyses. The remaining database consisted of 174 participants, of whom 95 (55%) had suffered from venous thrombosis. More than half (52%) of these participants had experienced one thrombotic episode, 24% had experienced two episodes and another 24% had experienced 3 or more episodes of venous thrombosis. The remaining 79 participants (45%) did not have a history of venous thrombosis. The sample consisted of 94 women (54%) and 80 men (46%). Ages were between 26 and 87 years of age, with a mean of 53 years. Within the sample 62 participants (35.6%) had the factor V Leiden mutation, 53 participants (30.5%) had protein C deficiency, 26 participants (14.9%) had antithrombin deficiency, 20 participants (11.5%) had protein S deficiency and 13 participants (7.5%) had factor V Leiden in combination with one of the other defects.

Of the 55 non-responders, 6 individuals had moved house and could not be reached, 4 were deceased and 3 were incapable of completing the questionnaire due to illness. Non-responders were slightly younger than responders (48 vs. 53 years). Non-

responders did not differ from responders with respect to gender, type of thrombophilia or history of venous thrombosis.

Illness perceptions

Table 1 presents means and 95% confidence intervals for the means on the subscales of the IPQ-R. Intercorrelations between the subscales of the IPQ-R and Cronbach's alphas are depicted in Table 2. The internal consistencies of the acute/chronic timeline, consequences, illness coherence, personal control and emotional representation subscales were satisfactory, ranging from .68 to .80. The cyclical timeline subscale originally had a Cronbach's alpha of 0.61. After removing item 31 ("Venous thrombosis is very unpredictable"), the internal consistency improved to .69. The low internal consistency of the treatment control subscale (.47) could not be improved by item reduction, so it was decided to leave this subscale out the further analyses.

Table 1 Means and 95% confidence intervals for means on the subscales of the IPQ-R, for participants with and without a history of venous thrombosis, and all participants

IPQ-R subscale	Thrombosis history (N= 95)	No thrombosis history (N=79)	All participants (N = 174)
Identity	4.3 (3.8-4.9)	3.6 (3.1-4.1)	4.0 (3.6-4.4)
Timeline acute/chronic	3.4 (3.2-3.6)	3.3 (3.1-3.4)	3.3 (3.2-3.5)
Consequences	3.1 (3.0-3.3)	3.2 (3.0-3.2)	3.1 (3.0-3.2)
Personal control	3.2 (3.0-3.3)	3.2 (3.1-3.3)	3.2 (3.1-3.3)
Illness coherence	3.7 (3.5-3.8)	3.3 (3.2-3.5)	3.5 (3.4-3.6)
Timeline cyclical	2.9 (2.6-2.9)	2.9 (2.7-3.0)	3.0 (2.7-2.9)
Emotional representations	2.6 (2.4-2.7)	2.5 (2.4-2.6)	2.5 (2.4-2.6)

On the identity subscale, participants attributed a mean of 4.0 symptoms to venous thrombosis. The symptoms that were mentioned most often were pain (87% of individuals reported that this symptom was associated with venous thrombosis), fatigue (65%), breathlessness (51%), and loss of strength (43%). A series of *t* tests was used to detect differences in illness perceptions between participants with and without a history of venous thrombosis. No differences on the subscale identity were detected between participants with and without a history of venous thrombosis. On the other subscales, a significant difference between individuals with and without a history of venous thrombosis could be detected only on the illness coherence subscale (mean 3.7 vs. 3.3, $p < 0.01$, 95% CI of the difference (0.1, 0.6)). This suggests that individuals who have a personal experience with venous thrombosis feel they have a better understanding of the disease.

In terms of perceived causes of venous thrombosis, the causes that were reported most often (the ones with the greatest proportions of participants who agreed or strongly agreed) were heredity (96%), immobilization (92%), surgery (90%), bed rest (85%), and lack of exercise (84%). On the open-ended question, the most frequent answers fell into the categories of heredity (67%), immobilization (59%), and surgery/accident (40%).

Analysis of covariance revealed that differences between groups with different types of thrombophilia could be detected only on the subscale personal control, after controlling for thrombosis history ($F(5,174) = 2.96, p < 0.05$), which was due to a differences in scores of participants with antithrombin deficiency and factor V Leiden.

Table 2 Pearson correlations between the IPQ-R subscales, risk perception, and thrombosis worry

	Identity	Timeline acute/chronic	Consequences	Personal control	Illness coherence	Timeline cyclical	Emotional representations	Risk perception	Worry
Identity	-	.16*	.26**	.04		.18*	.29**	.15*	.25**
Timeline acute/chronic		-	.14	.03	-.16*	.24**	-.02	.07	.06
Consequences			-	-.02	-.23**	.33**	.49**	.11	.31**
Personal control				-	.10	.07	-.14	.00	-.07
Illness coherence					-	-.37**	-.41**	.20*	.09*
Timeline cyclical						-	.22**	-.04	.10
Emotional representations							-	.13	.53**
Risk perception								-	.55**
Worry									-
Cronbach's alpha		.80	.68	.73	.75	.69	.85		

* p < 0.05

** p < 0.01

Thrombosis worry and risk perception

T-tests revealed that participants with a history of venous thrombosis had a significantly higher perception of their risk of getting venous thrombosis again (10.6 vs. 8.1, $p < .001$, 95% CI of the difference (1.6, 3.4)), and were significantly more worried about getting venous thrombosis again (8.0 vs. 6.2, $p < .01$, 95% CI of the difference (0.8, 2.9)) than participants without a history of venous thrombosis. Analyses of covariance revealed that, after controlling for age, thrombosis history was still a significant predictor of risk perception and worry scores (risk perception: $F(2,168) = 33.64$, $p < 0.001$, 95% CI of the difference (1.6, 3.4); worry: $F(2,168) = 11.41$, $p < 0.001$, 95% CI of the difference (0.8, 2.9)).

Risk perception and worry scores for the different types of thrombophilia are depicted in Figures 1 and 2. As can be seen in these figures, participants with antithrombin deficiency had higher scores on both perceived risk and thrombosis worry. Analyses of covariance revealed that, after controlling for the effect of thrombosis history and age, type of thrombophilia was still a significant predictor of perceived risk; $F(4,168) = 2.78$, $p < 0.05$. Scheffé's post-hoc tests revealed that this effect was mainly due to a difference in mean scores between antithrombin deficiency and Factor V Leiden. Scores for worry did not differ significantly between the different types of thrombophilia; $F(4,168) = 0.55$, $p = .70$.

Figure 1: Mean scores and 95% confidence intervals for means on risk perception for the different types of thrombophilia

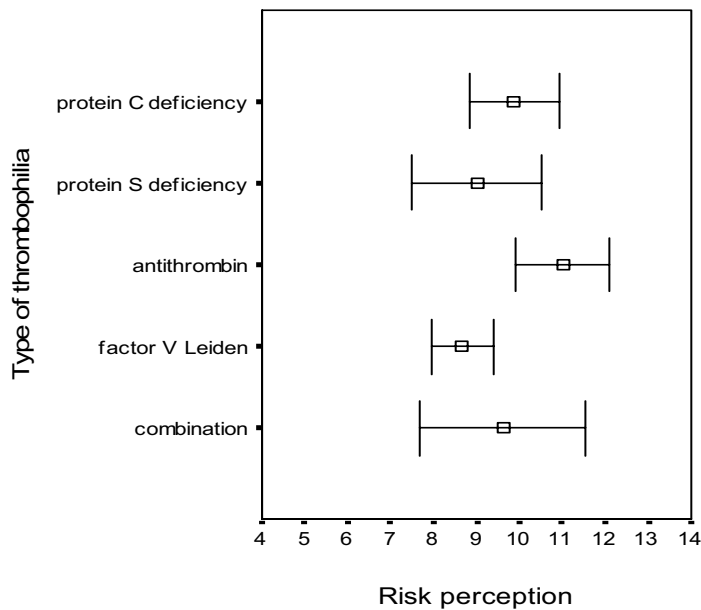
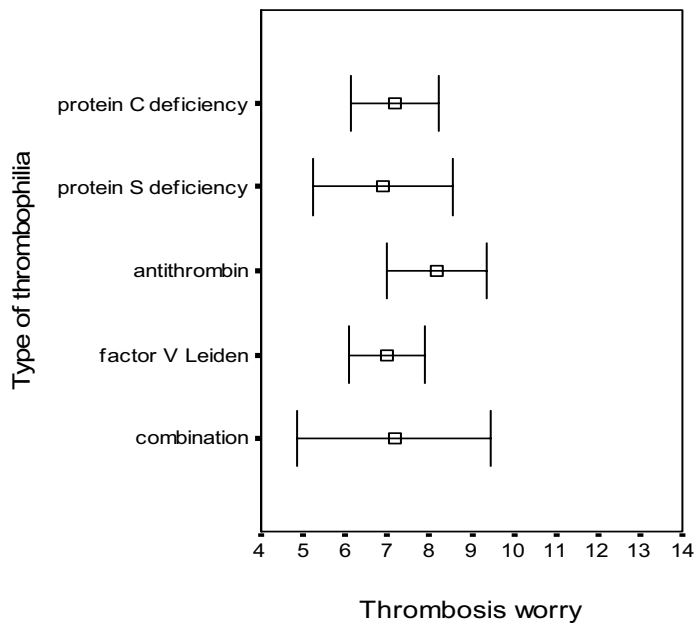


Figure 2: Mean scores and 95% confidence intervals for means on thrombosis worry for the different types of thrombophilia



Associations between illness perceptions, perceived risk, and thrombosis worry

Table 2 shows correlations between the illness perceptions, perceived risk, and thrombosis worry scores. The attribution of more symptoms to venous thrombosis was related to a belief in a longer timeline, more serious consequences, a stronger belief in a cyclical timeline, stronger emotional representations and a less coherent understanding of the disease. A belief in a longer duration was related to a stronger belief that the illness comes and goes over time. A belief in more serious consequences of venous thrombosis was related to a less coherent understanding of the disease, a stronger belief in a cyclical timeline and stronger emotional representations. A more coherent understanding of venous thrombosis was related to weaker emotional representations and a weaker belief in the cyclical timeline of venous thrombosis.

Perceived risk was positively related to illness identity and illness coherence. Thrombosis worry was also related to the attribution of more symptoms to venous thrombosis, as well as a belief in more serious consequences, a less coherent understanding of the disease, and stronger emotional representations. Risk perception and worry were positively correlated with each other ($r = .55$).

Regression analyses

Two-stage regression analyses were performed to assess the independent associations of the illness perceptions with perceived risk and thrombosis worry (see Table 3). Because the emotional representations subscale was highly correlated with thrombosis worry, it was decided to leave this subscale out of the regression analysis to avoid colinearity.

Results of the regression analysis of perceived risk revealed that the demographic and illness-related variables explained 19% of variance, whereas the illness perceptions explained 5%. The full model was significant, $p < 0.001$. Both younger age and a positive history of venous thrombosis were strong predictors of perceived risk scores. The IPQ-R subscale that contributed most to the regression equation was illness coherence .

For thrombosis worry, demographic and illness-related variables accounted for 7% of the variance whereas the illness perceptions explained 12% of the variance. The significance of the total model was $p < 0.001$. Of the demographic and illness-related variables, only a history of venous thrombosis contributed significantly to the regression equation. Beliefs in more symptoms and more serious consequences of venous thrombosis were the most important predictors of thrombosis worry.

Table 3. Two-stage regression analyses testing the value of the illness perceptions in predicting risk perception and thrombosis worry

Dependent variable	Predictors	Regression coefficients		t
		Unstandardized B (95% CI)	Standardized Beta	
Risk perception	Step 1			
	Age	-.04 (-.08, -.01)	-.20	-2.73**
	Type of thrombophilia	-.08 (-.42, .25)	-.04	-.47
	Thrombosis history	2.29 (1.28, 3.29)	.42	5.66***
	$\Delta R^2 = .19$			
	F = 12.64***			
	Step 2			
	Identity	.09 (-.11, .29)	.07	.87
	Timeline	.27 (-.29, .83)	.07	.95
	Consequences	.42 (-.42, 1.26)	.08	.99
Personal control	-.15 (-.89, .59)	-.03	-.39	
Illness coherence	.73 (-.03, 1.49)	.16	1.90*	
Timeline cyclical	-.05 (-.78, .67)	-.01	-.13	
Emotional representations	.51 (-.25, 1.27)	.12	1.32	
$\Delta R^2 = .05$				
F = 4.78***				
Thrombosis-related worry	Step 1			
	Age	-.01 (-.05, .03)	.01	.16
	Type of thrombophilia	.10 (-.28, .48)	.04	.51
	Thrombosis history	1.98 (.87, 3.01)	.27	3.39**
	$\Delta R^2 = .07$			
	F = 4.10**			
	Step 2			
	Identity	.22 (.00, .44)	.15	2.0*
	Timeline	-.08 (-.70, .54)	-.02	-.25
	Consequences	1.39 (.54, 2.24)	.25	3.23**
Personal control	-.27 (-1.09, .55)	-.05	-.65	
Illness coherence	-.36 (-1.15, .43)	-.07	-.89	
Timeline cyclical	.05 (-.75, .85)	.01	.12	
$\Delta R^2 = .12$				
F = 4.21***				

Note: The IPQ-R dimension emotional representations was not entered into the regression analysis for thrombosis-related worry because of a high correlation with thrombosis-related worry, * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Discussion

In this study, the Common-Sense Model (CSM) was used to explore the nature of the cognitive representations of venous thrombosis formed by thrombophilic individuals, and to evaluate how these representations are associated with risk perceptions and thrombosis worry. Perceived risk and thrombosis worry were found to be significantly higher for participants with a history of venous thrombosis than for individuals without a history of venous thrombosis. Furthermore, perceived risk and worry scores were higher for participants with antithrombin deficiency than for participants with any of the other thrombophilias. After controlling for thrombosis history and age, analyses of covariance revealed that this group difference in perceived risk was still present. This group difference reveals realistic perceptions, because individuals with antithrombin deficiency appear to have the greatest venous thrombotic risk of all the single thrombophilias (30;31). This finding indicates that knowledge of thrombophilic individuals about their risk of venous thrombosis is generally good. On the other hand, individuals with a combination of factor V Leiden and other defects do not have higher perceptions of their thrombotic risk than individuals with single defects even though biomedical evidence indicates that combined defects pose the greatest thrombotic risk (29).

Few differences in illness perceptions were identified between individuals with a history of venous thrombosis and individuals without a history of venous thrombosis. The only statistically significant difference in scores was on the illness coherence subscale. In general, it appears that asymptomatic individuals have realistic expectations about the experience of having venous thrombosis. However, despite their realistic beliefs about venous thrombosis, they tend to score lower on illness coherence, indicating that thrombophilic individuals without a history of venous thrombosis do not feel that they have a coherent understanding of the illness. More information about venous thrombosis could help to strengthen their knowledge about the illness to make them feel more confident in understanding the illness. The causes of venous thrombosis that were endorsed most frequently by the participants were heredity, immobilization, and surgery, which is in line with the view of venous thrombosis as a multicausal disease that is caused by both genetic and environmental risk factors (46).

We hypothesized that perceived risk would be associated with ‘consequences’ and ‘illness coherence’ beliefs, as well as with younger age and a history of venous thrombosis. The findings partially support these hypotheses. First, correlational patterns revealed that perceived risk was positively associated with illness coherence, but it was not correlated with consequence beliefs. Unexpectedly, perceived risk was associated with higher identity scores, indicating that those who associated venous thrombosis with a greater number of symptoms tended to have higher risk perceptions. The results of the regression analyses indicate that illness perceptions only have a modest contribution in accounting for the variance in perceived risk scores, with illness coherence as the only sig-

nificant predictor. As expected, younger age and a history of venous thrombosis were predictors of perceived risk scores.

We predicted that worry would be associated with all IPQ-R subscales, with the strongest associations for the identity and consequences subscales. Worry was indeed found to be significantly associated with identity and consequences. Regression analyses revealed that illness perceptions could account for a greater amount of variance in thrombosis worry scores than risk perception scores. Also, as predicted, identity and consequences were both modest but significant predictors of worry. Demographic and illness-related variables explained only a modest amount of variance in thrombosis worry scores with thrombosis history being the only significant predictor. These results indicate that the cognitive components of illness representations have a stronger association with illness-related affect, rather than with more reasoned, cognitive appraisals of disease risk. Other variables, such as a personal history of venous thrombosis, seem to be better predictors of risk perception.

This is one of the first studies that uses the Illness Perception Questionnaire-Revised to assess the illness perceptions of individuals at risk of a disease. The treatment control subscale showed a low internal reliability ($\alpha = .47$) that could not be improved by item reduction, and it was therefore removed from subsequent analyses. This might give an indication that thrombophilic individuals do not have a clear understanding of the treatment of venous thrombosis. Some other subscales showed only moderate internal consistency, such as the illness coherence subscale. Rees and colleagues (18) encountered similar difficulties regarding the internal consistency of some of the subscales. A further issue is that the emotional representations subscale was highly correlated to thrombosis worry. Although thrombosis worry reflects persistent concern about developing the disease and the emotional representations subscale reflects the affective response to venous thrombosis, it seems that in the present form, the scales are not differentiated enough from each other. Furthermore, the control subscales of the IPQ-R measure control over the recovery of venous thrombosis. In populations at risk of a disease, beliefs about control over the prevention of a disease are probably more relevant. With the original wording of the IPQ-R, it appears to be difficult to capture the illness perceptions of individuals at risk of a disease. Further research should aim at refining the subscales so that they adequately capture illness perceptions in at-risk populations. The development of a new version of the IPQ-R, specifically for individuals 'at risk', could be a possible outcome.

Non-responders were slightly younger than responders in this study, which may have biased the results. Since younger people perceived their risk for venous thrombosis as higher than did older people, the perceived risk means observed in the present study are likely to be somewhat tempered. Another limitation is the cross-sectional nature of the study, which precludes definitive interpretations of the directionality of the influences among perceived risk, worry, and illness perception components.

Further research, preferably with a longitudinal design, and measurements of illness perceptions, risk perceptions, worry, and health behavior before and after genetic counseling, could help to clarify the exact nature of the value of the CSM in explaining the regulation of illness risks. A better understanding of the processes involved in how individuals form their risk perceptions and worry about a health threat could help clinicians in predicting which individuals may exhibit high levels of distress or hold misconceptions about the magnitude of their risk. These insights also could help to increase understanding of the factors that are involved in health behaviors to reduce the risk of a disease.

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