Values and preferences towards the use of prophylactic low-molecular-weight heparin during pregnancy: a convergent mixed-methods secondary analysis of data from the decision analysis in shared decision making for thromboprophylaxis during pregnancy (DASH-TOP) study

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Abstract

Background Venous thromboembolism (VTE) in pregnancy is a major cause of maternal morbidity and mortality, and the use of preventive low-molecular-weight heparin (LMWH) can be challenging. Clinical guidelines recommend eliciting pregnant individuals' preferences towards the use of daily injections of LMWH and discussing the best option through a shared decision-making (SDM) approach. Our aim was to identify individuals' preferences concerning each of the main clinical outcomes, and categorize attributes influencing the use of LMWH during pregnancy.

Methods Design: Convergent mixed-methods.

Participants: Pregnant women or those planning a pregnancy with VTE recurrence risk.

Intervention: A SDM intervention about thromboprophylaxis with LMWH in pregnancy.

Analysis: Quantitatively, we report preference scores assigned to each of the health states. Qualitatively, we categorized preference attributes using Burke's pentad of motives framework: act (what needs to be done), scene (patient's context), agent (perspectives and influence of people involved in the decision), agency (aspects of the medication), and purpose (patient's goals). We use mixed-method convergent analysis to report findings using side-by-side comparison of concordance/discordance.

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Results We comprehensively determined preferences for using LMWH by pregnant individuals at risk of VTE: through value elicitation exercises we found that the least valued health state was to experience a pulmonary embolism (PE), followed by major obstetrical bleeding (MOB), deep vein thrombosis (DVT), and using daily injections of LMWH (valued as closest to a 'healthy pregnancy'); through interviews we found that: previous experiences, access to care (scene) and shared decision-making (agent) affected preferences. LMWH's benefits were noted, but substantial drawbacks were described (agency). For participants, the main goal of using LMWH was avoiding any risks in pregnancy (purpose). Side-by-side comparisons revealed concordance and discordance between health states and motives.

Conclusions Mixed-methods provide a nuanced understanding of LMWH preferences, by quantifying health states preferences and exploring attributes qualitatively. Incorporating both methods may improve patient-centered care around preference-sensitive decisions in thromboprophylaxis during pregnancy.

Keywords Values, Preferences, Venous thromboembolism, Low-molecular-weight heparin, Pregnancy, Shared decision-making

Background

Pregnancy is a prothrombotic state that increases the risk of venous thromboembolism (VTE) by four to five times during pregnancy and up to 20–80 times in the postpartum period [1–3]. VTE is a major cause of death in pregnancy and the peripartum period worldwide [2, 4, 5]. Furthermore, individuals with a prior history of VTE and those with congenital and acquired thrombophilia are at an increased risk of VTE during pregnancy and the postpartum period [1, 2, 5, 6]. Low-molecular-weight heparin (LMWH) is the preferred agent for thromboprophylaxis [3, 6]. However, despite negligible fetal concerns, adverse events and costs remain important considerations [6]; furthermore, it involves once- or twice-daily subcutaneous injections that could result in local reactions, bruising and pain [7–9]. Therefore, the decision to use LMWH thromboprophylaxis is very preference-sensitive. Preference-sensitive decisions occur in situations where the evidence for the superiority of one treatment over another is either not available or does not allow differentiation, and where the best choice between two or more valid approaches depends on how individuals value their respective risks and benefits [10]. Given the lack of high-quality evidence to make strong recommendations, the 2018 American Society of Hematology (ASH) guidelines encourage the incorporation of patient values and preferences while considering the use of LMWH for thromboprophylaxis during pregnancy as part of a shared decision-making (SDM) approach [6, 11].

There is limited insight from the research literature [8] into how pregnant individuals at risk of VTE weigh the benefits and harms of LMWH use while making decisions regarding thromboprophylaxis. Furthermore, the most widely used methods to collect patient preferences are based on quantitative instruments such as visual analogue scales (VAS) [7, 12], direct choice experiments [7, 12], or questionnaires [12–14]; leaving qualitative methods underused [8, 15] due to the lack of guidance on how to collect and represent these preferences.

One of the main advantages of the SDM approach is to personalize conversations around treatment options considering that patient preferences differ. In the SDM approach, especially with the use of decision aids [16, 17], by using quantitative instruments patients are able to clarify their preferences by indicating which health states are most important for them to experience or avoid and thus, reduce decisional conflict (uncertainty around clinical outcomes) [16]. However, other aspects that can influence the decisions are not typically addressed, like patient's personal context, treatment goals, and the influence of trusted friends and family members [16, 18]. If they are addressed at all, it's usually through qualitative methods [8, 13, 14, 16, 19–21]. Synthesizing qualitative findings or themes from individual studies is not a straightforward process, highlighting the utility of standardized qualitative frameworks that can more readily indicate the relative desirability or acceptability (i.e., preferences) of various attributes of treatment alternatives [22, 23]. One such framework is Kenneth Burke's Pentad of Motives theory, which categorizes preferences or attributes that influence a decision-making process [18, 24, 25]. Hence, mixed-methods are a key methodology for eliciting patients' preferences [8, 26, 27] and garnering a comprehensive understanding of the factors influencing decision-making. Consequently, this approach bears significant implications for clinical practice, as it facilitates SDM by tailoring interventions, to align with patients' values and preferences. Such interventions could potentially lead to greater satisfaction and adherence, by addressing patient's unique needs and condition [18, 28, 29].

The goal of our study was to facilitate the clarification of treatment and outcome preferences for individuals

at risk of thrombosis during pregnancy using a mixed methods approach.

Methods

Study setting and intervention

To support pregnant individuals in deciding whether to use LMWH for thromboprophylaxis, researchers and clinicians from Canada, U.S.A. and Spain developed a shared decision-making intervention- Decision Analysis in SHared decision making for Thromboprophylaxis during Pregnancy (DASH-TOP) [30].

The DASH-TOP intervention included three components: 1. a decision aid with information about the risks and benefits of using LMWH to prevent VTE; 2. three value elicitation exercises to provide patient preferences toward four predefined health states, [9] which represent the primary clinical outcomes for those at risk of recurrent VTE during pregnancy: experiencing major obstetrical bleeding, deep vein thrombosis (DVT), pulmonary embolism, and the use of daily injections of LMWH prophylaxis in pregnancy; and, 3. a personalized decision analytic model showing potential changes in the patient's quality of life (measured in QALYs) based on their choice of using LMWH or opting for expectant management [30].

Participants provided their preference scores through value elicitation exercises. Additionally, we conducted semi-structured interviews to assess their decision-making process. The intervention's efficacy in supporting decision-making was assessed in women at risk of VTE during pregnancy, from Canada and Spain, between 2019–2021, in the Decision Analysis in SHared decision making for Thromboprophylaxis during Pregnancy (DASH-TOP) study [30]. The findings of the DASH-TOP intervention indicate that the use of this SDM approach led to reductions in decisional conflict, increased patient satisfaction, and improved patient self-efficacy in the decision-making process [30]. However, participant preferences toward the use of LMWH were not reported in this publication [30], and thus were the current study's objective.

Study objectives

In this secondary analysis of participant data from the original DASH-TOP study [30], our objectives are: (i) to examine the preference scores assigned by participants to each of the health states as part of the three distinct value elicitation exercises, and (ii) to deductively categorize the attributes ("motives") that influenced the decision-making process, as reported in the semi-structured interviews, using Burke's pentad of motives.

Study design

This secondary analysis follows a mixed-methods convergent design [27, 31]. We first collected quantitative data (preference scores rated in the value elicitation exercises during the intervention) and, subsequently generated qualitative data from semi-structured interviews conducted after the intervention.

We analyzed, in parallel, the quantitative statistical results of the preference scores, and the qualitative data, using Burke's pentad of motives (a framework used to explore individuals' motives to carry out an action, in this case a health decision, as explained below [24]). We compare the two datasets using the side-by-side comparison approach [27, 31]. The interpretation of the findings consists of concordance/discordance assessments between the two datasets; in which qualitative findings (Burke's motives) are compared to the quantitative results (health states preference scores). Figure 1 Mixed-methods convergent side-by- side design.

Participants

The sample consisted of fifteen participants with a prior VTE who were either pregnant or planning pregnancy at the time of enrollment and who had been referred for counseling regarding prophylactic LMWH in the antenatal period. To categorize the participants' risk levels for subsequent VTE, we considered a history of thrombophilia, unprovoked VTE, or VTE associated with a hormonal risk factor to predict higher risk. Those with a prior VTE associated with a non-hormonal temporary provoking risk factor and no other risk factors were classified as being at lower risk. Eligible participants were recruited from hospitals in Canada (1 site) and Spain (4 sites). The study was approved by their respective ethical committees (Hamilton Integrated Research Ethics Board (project id# 5425) and Institut de Recerca de l'Hospital de la Santa Creu i Sant Pau – IIB Sant Pau (project id# IIBSP-TDC-2018–02). All participants provided informed consent.

Data collection

Prior to the intervention, we used a questionnaire to collect participants' sociodemographic and clinical data, including participants' age, level of education, pregnancy status (pregnant or planning to get pregnant), risk of recurrent VTE (high or low), details regarding prior VTE, and experience with LMWH in their prior VTE (see full questionnaire in Supplementary Material 1).
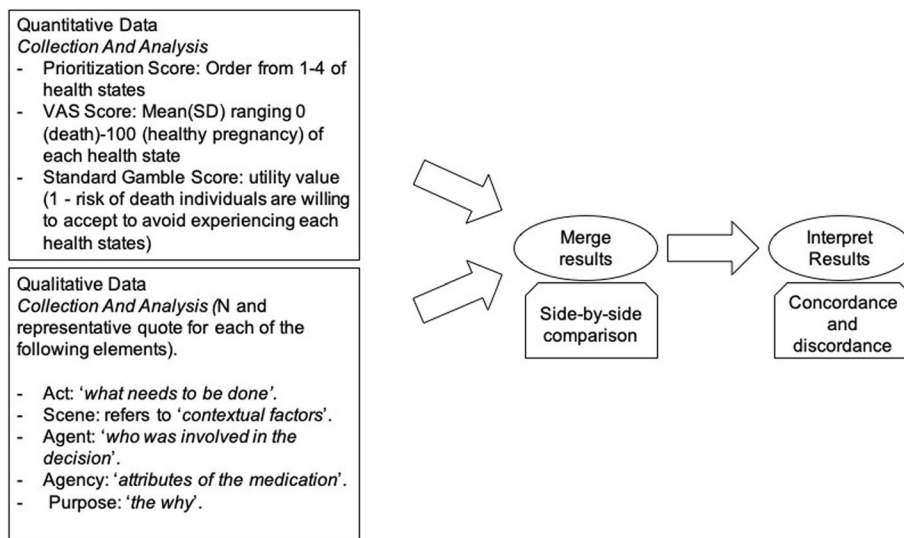
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Fig. 1 Mixed-methods convergent side-by- side design

Quantitative data

During the intervention, individuals participated in three value elicitation exercises to determine the significance of predefined health states in determining preferences. These health states included: i) daily injections of LMWH, ii) experiencing a major obstetrical bleed, iii) experiencing DVT, and iv) experiencing pulmonary embolism. The exercises were as follows: i) rank ordering the health states from 1 to 4, where 1 represented the health state closest to a 'healthy pregnancy' and 4 represented the state closest to 'death'; ii) using a visual analogue scale (VAS) ranging from 0 (representing 'death') to 100 (representing a 'healthy pregnancy'); and iii) applying a standard gamble to evaluate preferences under conditions of uncertainty, a method grounded in expected utility theory [32, 33] that uses the risk of death a patient is willing to take to avoid experiencing a particular health state to calculate a utility value for that health state. For further details on these value elicitation exercises, refer to the original study protocol [30].

Qualitative data

Once the intervention was completed (post-intervention), we interviewed participants and asked them about their engagement in the decision-making process and the factors that influenced their final decision (see full interview guide in Supplementary Material 1). The interviews were audio-recorded (length: between 20 and 40 min) and transcribed verbatim. Spanish interview transcriptions were translated into English by an experienced bilingual translator. Transcripts were transferred to NVivo software (Version 12, QRS International).

Data analysis
Quantitative data

We reported the preference scores obtained from the three value elicitation exercises as follows: i) for the rating exercise, we provided the order in which the four health states were ranked (from 1–4); ii) for the VAS, we reported the mean and standard deviation (SD) for each of the four health states; and, iii) for the standard gamble, we reported the utility calculated as (1—risk of death that women are willing to accept in order to avoid experiencing each of the particular health states during their pregnancy). We used non-parametric tests (Kruskal- Wallis test for categorical variables and Mann–Whitney test for dichotomic variables) to assess statistical differences between the scores for each of the value elicitation exercises and the sociodemographic and clinical variables.

Qualitative data

Categorization and synthesis of the qualitative data was achieved through the use of directed content analysis [34]. We used Kenneth Burke's Pentad of Motives [24] to deductively categorize patient preferences toward using LMWH to prevent VTE during their pregnancy. Burke's pentad of motives is a framework for analyzing discourse and understanding people's motivations and justifications for actions [18, 24, 25]. Burke's Pentad considers five motives: i) Act (what needs to be done); ii) Scene (the context in which it is done); iii) Agent (who was involved in the decision); iv) Agency (aspects of the medication itself); and v) Purpose ('the why' referring to individual's

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Table 1 Burke's pentad of motives categories

Act The action itself. It refers to the question of 'what needs to be done' in order to manage the risk of presenting VTE during pregnancy. E.g. "continuing my current medication regimen"
Scene The context surrounding the act. This category involves contextual factors (in a broad sense, like access to healthcare) and personal factors (e.g., self-perception of the circumstances under which they are making the decision, anxiety about making a wrong decision, or self-management of uncertainty). These preferences are arbitrary and depend on the patient. E.g. "given my income, medical condition and risk factors"
Agent The people performing the act. It refers to 'who was involved in the decision'. E.g. "the doctor recommended this medication"
Agency The means used to carry out the act. It refers to 'attributes of the medication', in this case thrombophylaxis with LMWH. E.g. "this drug has fewer side effects"
Purpose The goal or objective trying to be achieved. It refers to 'the why'; it describes occasions when a participant attributes desirability to the results that LMWH may achieve or a favorable alignment with patient goals of the care plan. E.g. "to prevent blood clots and strokes"

goals). For detailed descriptions of each motive, refer to Table 1.

Three authors (MLG, DG, EG) who were familiar with the framework, independently and in pairs, identified preferences from participant interview transcripts. Preferences were defined as expression of any argument, reason, or explicit justification for why the participant preferred one treatment plan over another (i.e., preventive pharmacological treatment with daily injections of LMWH vs. no preventive pharmacological treatment). They also provided brief interpretations for each motive and later grouped these interpretations into categories. An 'unclear' option was included to capture any potential category not covered by the Burke's pentad motives. We reported each of the motives and categories in a descriptive format, providing representative quotes to justify our findings. Finally, we provided a table summarizing the main aspects of each of Burke's Pentad motives.

Mixed-methods comparison

We used descriptive statistical analysis to report the frequency of appearance of each of Burke's Pentad motives by the following dependent variables: level of education; pregnancy status; risk of recurrent VTE; and location of previous VTE event. We used non-parametric tests (Kruskal- Wallis test for categorical variables and Mann–Whitney test for dichotomous variables) to assess statistical differences between the Burke's motives and the sociodemographic and clinical variables.

We provided side-by-side comparisons in a tabulated format, of the preference scores for the four health states and their relation to the attributes (Burke's motives) of the preferences, determining whether they confirm or disconfirm the associations.

Results

We interviewed seven participants in Canada and eight in Spain. The mean age of participants was 32.5 years; most participants (9, 60%) had a university education,

and nine (60%) were not currently pregnant but planning for a pregnancy at the time of referral for counseling. The majority were considered to be at high risk for VTE (12, 80%), and had previous experience with LMWH (12, 80%). We provide additional sociodemographic information, clinical characteristics, and participants' previous experience with VTE and LMWH (Table 2).

Quantitative data – value elicitation exercises

For the rank ordering exercise, we used anchor states of 'healthy pregnancy' and 'death' as the best and worst potential outcomes. With regards to the intermediate outcomes being assessed, the majority of participants (87%) rated the health state 'using daily injections of prophylactic LMWH during pregnancy' as the best. This was followed by experiencing DVT (in 60% of participants). Experiencing a major obstetrical bleed and experiencing a pulmonary embolism were equally rated as the worst outcomes (40% participants). No statistical differences were observed between the rank ordering exercise and any of the sociodemographic and clinical characteristics (Supplementary Material 2, Table S1).

The VAS scores followed the same pattern: using daily injections of prophylactic LMWH during pregnancy (mean $=75.07$ SD $=21.68$) had the score closest to 100 ('healthy pregnancy'), followed by DVT (mean $=40.40$ SD $=26.57$), and major obstetrical bleed (mean $=39$ SD $=20.76$) and pulmonary embolism (mean $=26.73$ SD $=14.59$) scores closest to 0 ('death'). Statistical differences were observed between the VAS score for the health state of using daily injections during pregnancy and the pregnancy status; pregnant participants rated daily LMWH injections as being 'closer to death' than those planning pregnancy (57.17 vs 87). For the other sociodemographic and clinical characteristics, no statistical differences were observed (Supplementary Material 2, Table S1). Figure S1 (Supplementary Material 2) shows a histogram with the VAS scores for each participant.

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Table 2 Sociodemographic and clinical characteristics of participants

Demographic characteristics	N (%)
Age, mean (SD)	32.5 (6.3)
Level of education	
High school	1 (7)
College	3 (20)
Some university	2 (13)
University	9 (60)
Country of residence	
Canada	7 (47)
Spain	8 (53)
Clinical Characteristics	
Pregnancy status	
Pregnant	6 (40)
Planning pregnancy	9 (60)
Risk of recurrent VTE	
High	12 (80)
Low	3 (20)
Previous VTE Experience	
Number of previous events	
1	12 (80)
2	3 (20)
Type of previous event	
Leg	7 (47)
Lung	5 (33)
Both	2 (13)
Other	1 (7)
Previous use of LMWH	
Yes	12 (80)
No	3 (20)
LMWH difficult or troublesome	
Yes	7 (47)
No	5 (33)
Not applicable	3 (20)
Fear of needles	
Yes	2 (13)
No	10 (67)
Not applicable	3 (20)

Finally, in the standard gamble exercise, participants rated non-fatal health states as follows: daily injections of LMWH during pregnancy = 0.893, DVT = 0.871, major obstetrical bleed 0.833, and pulmonary embolism = 0.823. Of note, participants with university or high school degrees had a statistically significant higher standard gamble utility score for daily injections of LMWH during pregnancy (0.95) than those with college or some university degrees (0.77 and 0.71, respectively); similarly, participants in Spain had a significantly higher standard gamble utility score for pulmonary embolism (0.93) compared with those in Canada who reported a lower utility of (0.68). For the other sociodemographic and clinical characteristics no statistical differences were observed (Supplementary Material 2, Table S1). Figure S2 (Supplementary Material 2) shows a histogram with the SG scores for each participant.

Qualitative data – Burke's pentad of motives
We identified 172 preferences in the interviews. Scene and agent preferences were the most frequent (26% each), followed by agency (22%), act (16%), and purpose (10%). There were no preferences tagged as unclear. In Table 3 we have presented representative quotes from participants (showing their risk of VTE and country) for each of the categories identified for Burke's motives. No statistical differences were observed between the number of act, scene, agent, and purpose motives and any of the sociodemographic and clinical characteristics; however, for agency, statistical differences were observed between the number of agency preferences and the country (Spain 70% and Canada 30%) (Supplementary Material 2, Table S2).

Act
The act motive yielded 28 preferences and was reported by ten participants. Four primary actions for this step of the decision-making process were identified in this motive.

The first action was the most frequently reported and refers to the acquiring of more information from clinicians [P1] [P11]. Specifically, on: the effect of LMWH in those at lower vs higher risk of experiencing a VTE event [P12]; on drug administration and other effects of the drug [P9]; questions about practical issues like traveling while using LMWH [P13]; and on the best gestational age for administration of LMWH [P2] [P11].

The second action is the acceptance of their situation in which taking the medication is the expected action. Some participants assumed they were going to have to take it, while others were not aware that they could opt out of taking LMWH [P1][P3].

The third action was related to considering other treatment options (such as oral medications or expectant management). Participants indicated that their choice of options was influenced by the cause of their VTE. For instance, some had experienced VTE while taking contraceptive pills but had ceased using them by the time of the interview, which made them feel less vulnerable to that risk factor. Consequently, they sought less troublesome alternatives, including oral medications, regular check-ups with ultrasound of the lower extremities, or adopting healthier lifestyle behaviors [P12].

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Table 3 Representative quotes for each them of the motives scene, agent, act, agency and purpose

Motive (N, % of preferences)	Category (N, % of participants)	Representative Quote		
		Quote [ID participant]	High/Low Risk of VTE	Location (Canada, Spain)
Act (28,16%)	*Acquiring more information from clinicians (8, 53%)*	*"I still have to meet with my OB. I feel that I want a lot of knowledge about the decision that I'm making and what my potential risks are, so I can try and mediate them you know every single day"* [1]	High	Canada
		"Also, being able to have more time to be able to speak with my hematologist. Because I went for an analysis and from there he tells me that I have to take heparin for my entire pregnancy, I was shocked, and I don't have time to think it through. Now with all this information I would like to be able to discuss it with my hematologist, and not make the decision alone. For me, it is very important that there is a person like you who explains all the risks and benefits to me; for example, I did not know about the major obstetric hemorrhage." [11]	Low	Spain
		"for me the information on the risk that has been given in this study is very important, because of course the information on the risk, which for me is very important, is information that I did not have. I thought that since they tell you that you have to use heparin yes or yes, it was because it is because there is a very, very high risk" [12]	High	Spain
		"I would like more information on what is the most suitable dose for me. I would also like them to teach me how to use heparin, to know how I should prick myself, especially to prevent itching. I would also like to have information regarding abortion, especially in the early stages of pregnancy, because I have been told that with heparin this can improve. The effect of heparin on intrauterine development" [9]	High	Spain
		"I wish they had given me information for when I was traveling. After the thrombus, I went on vacation to California and they didn't give me any information; and then on the way back they told me that I should have taken heparin 12 h before traveling." [13]	High	Spain
		"Actually, I guess another question would be whether I need to take it pre-pregnancy or can I start when I get pregnant" [2]	High	Canada
		"Also, that there is a professional who teaches the technique of giving the injection (oblique puncture, that you have to take a pinch of the gut to puncture and puncture 5 cm from the navel, that you do not have to scratch when it stings or put ice, and let the air out of the syringe" [11]	Low	Spain
	Acceptance of their situation (4, 27%)	*"So, I feel like going on heparin would just be the thing that I have to do to stay healthy during that time"* [1]	High	Canada
		"Yea. Realistically, if I'm going to have to do, its going to have to become a part of my everyday routine. It's not like I'm going to have to sit down for two hours and inject myself. Diabetics do it everyday" [3]	Low	Canada

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Table 3 (continued)

Motive (N, % of preferences)	Category (N, % of participants)	Representative Quote		
		Quote [ID participant]	High/Low Risk of VTE	Location (Canada, Spain)
	To consider other options (3, 20%)	*"On the one hand, I think I would rather be paying to do regular ultrasound scans on my leg (…), I'd rather be wasting my time to go for more tests than not having to prick. For example, in the previous case when I was switched to pills, I preferred the time I invested in measuring my levels, until I adjusted the dose, for example; it takes time to adjust, but I prefer it to using heparin. I know I can't take pills for my pregnancy but no one explains to you other alternatives that I can do instead of taking heparin, for example if I do sports or if I take baths with cold water."* [12]	High	Spain
	Burden of decision-making (2, 13%)	*"Definitely frustration that this is an added thing that I have to think about. I don't know, at least in my head, that other women don't have to think about. So that's definitely an added challenge and something for me that has been in my head for a while"* [6]	High	Canada
Scene (45,26%)	Personal previous experience of suffering a clot (13, 87%)	*"The seriousness of my previous situation makes me very afraid that it will happen again. I already know how heparin works, I'm going to do it for sure. So considering that I already have a risk of thrombosis; and, it is not only because of me but because of the baby. And it costs me nothing to put on a little prick every day that I know that will keep me well, not perfect, but stable, I can lead a normal life."* [8]	High	Spain
		"[…] having gone through my previous experience, it gives me more confident to take LMWH, for me it's not no uncomfortable to be injecting and it really relieves my anxiety to be doing something. Maybe I'm more conservative, but I think it really depends on how your previous experience was." [14]	High	Spain
		"My previous experience during my other pregnancy, that at first, I did not take it, and when I had the thrombus I was so afraid, the doctors told me that if I did not take it I could lose the baby, so I no longer doubt it. It is true that at the beginning during my pregnancy that I had to prick every day, it raised the idea of abortion, because I could not bear it and I thought on how many weeks pricking myself, "there are many pricks"; and then it was part of my routine […] My previous experience, I had such a bad time and I was so scared. Now seeing that the risk is so low and also that the benefit is not that much, I would think about not taking it, but I remember my experience and I would take it." [15]	High	Spain
	Anxiety and fears toward this decision (9, 60%)	*"My fear of pulmonary emboli is very big. I remember that the last time with my other pregnancy, I remember that the nurse told me look, it is impossible for you to have a clot if you take heparin, and that gives me peace of mind."* [14]	High	Spain
		"I knew I'd have to start taking the injections. And my main concern was the baby, of course. How is that affecting the baby? And I still lead with that concern… Uhhh… you know whether or not this is going to affect my baby. I was told no, its [LMWH] not going to affect but it's still there, that [sigh] when you think about it." [5]	Low	Canada

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Table 3 (continued)

Motive (N, % of preferences)	Category (N, % of participants)	Representative Quote		
		Quote [ID participant]	High/Low Risk of VTE	Location (Canada, Spain)
		"It makes me nervous. Because there is a lot of the unknown. Like I said before, there is no pregnancy that's perfect. You're always going to have different things that happen. I am more nervous about whether I am going to have a healthy pregnancy where I am going to be able to go to term and not have major bleeding. Or am I going to start this too early and is it going to stress me out that I am going to have a miscarriage. There's all those little 'what if's.' […] So, it's like I wanted this so bad and now I have to add in another factor – which makes me more nervous. Um. I think like any expecting mom, by the time you hit your last couple weeks you start thinking "Oh my god I have to go give birth", that's kind of scary. So in lieu of that normal anxiety, we now have another layer. So, I think it's just more of an anxiousness." [1]	High	Canada
	Personal disposition to risk aversion (4, 27%)	*"So, I'm not a very risky person. So, you know, if somebody wanted me to go on a rollercoaster, I'm 'okay, I don't want to go on a rollercoaster,' I like my feet on the ground. I think knowing that there is a risk of death by not doing anything, regardless if it's 10%, I still think 10% is very high […] I'm not really a risk averse person. There's some people that would rather take the risk than inject something into their body." [1]*	High	Canada
	Being pregnant or planning a pregnancy (3, 20%)	*"It is also true that I am not pregnant now, perhaps when I get pregnant this changes my perception." [12]*	High	Spain
	Access to health care (2, 13%)	*"Nor do I have a rutinary gynecologist, I do not have private insurance so when I go to the primary care center it is because there is something and I have to go, or the check-ups or Pap tests. So, I don't have a follow-up from anyone." [12]*	High	Spain
		"I appreciate that where I live is close to a specialist because otherwise if I was in a different area where there wasn't that same kind of resources, I think I'd be much more anxious. But because I live in an area where there's resources that are available to me, I think that I'm more comfortable with the final decision." [6]	High	Canada
Agent (45,26%)	Level of involvement (8, 53%)	*"I prefer to listen to what the doctor has to say about the benefits or no benefits of the treatment, and from there, between the two make a decision" [10]*	High	Spain
		"I want them to make the decision for me, but to inform me of everything. I trust more in a person who is dedicated to that, than in myself that I do not have any experience or knowledge" [14]	High	Spain
		"I usually make the decision in a very thoughtful way, I don't usually make it overnight. It takes a long time. First, I listen to the health professional, and then I make the decision myself" [11]	Low	Spain
	Decision-makers (11, 73%)	*"when I went to my doctor, I was the one who brought up pregnancy and whether there would be a higher risk of blood clots or something. And he was the one who was like "Okay, let's make an appointment." So he was the one who was supportive in allowing me to find what was best for me" [6]*	High	Canada

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Table 3 (continued)

Motive (N, % of preferences)	Category (N, % of participants)	Representative Quote		
		Quote [ID participant]	**High/Low Risk of VTE**	**Location (Canada, Spain)**
		"when I get pregnant, for example three months from now, the gynecologist will tell me that I have to use heparin, then I will have to tell her well, I don't feel like it, or I don't feel like it at all, then there I will have a conflict with the doctor" [12]	High	Spain
		"I would ask my mother, and take the decision together along with the information given to me about the risks" [P13]; and, "…also my husband, what he thinks. My husband, for example, he wants us to have another baby, yes or yes" [15]	High	Spain
	Other people's experiences (7, 47%)	*"Let's see when you want to get pregnant and more at my age you are involved in a thousand mothers' forums and there many have had to use heparin during their pregnancy" [14]*	High	Spain
		"my cousin had a baby last week and hemorrhaged really badly. So that was kind of swaying me towards not taking the meds." [2]	High	Canada
Agency (37, 22%)	Benefits			
	Has effect to prevent a DVT or PE (9, 60%)	*"Benefits being that I am less likely to end up with a DVT or pulmonary embolism." [6]*	High	Canada
	No harm for the baby (2, 13%)	*"Knowing that it won't be going through the baby. That there's no harm to the baby" [2]*	High	Canada
	More regular check-ups of their pregnancy (2, 13%)	*"I would have to go to the gynecologist more often so that they would see me if I have lumps on my legs or have an ultrasound" [13]*	High	Spain
		"(…) but they also have you more controlled that everything is going well, that the dose is correct" [10]	High	Spain
	Other: Low risk of bleeding, perception that LMWH has the effect to prevent miscarriage, and can stop the medication immediately (3, 20%)	*"And that there's a very low risk of bleeding, like a major bleed" [2]*	High	Canada
		"Although the information is lacking, heparin does prevent abortion. Before I got pregnant with my first child I had a miscarriage, and after taking heparin this prevented it." [9]	High	Spain
		"I can interrupt it before delivery immediately, not as with the sintrom [oral anticoagulants] that I have to interrupt progressively" [11]	Low	Spain
	Drawbacks			
	Scheduling injections (7, 47%)	*"Having to take the heparin everywhere you go. It becomes part of a ritual, so you first need to clean the area with cotton, then sit down to inject the heparin, it takes your time. You need to be doing this at home, you can't go to a restaurant and then put it in the bathroom." [12]*	High	Spain
	Pain, bruising and aesthetics (6,40%)	*"The itching and bruising" [9]*	High	Spain
		"And then, I've always wanted to have a cute pregnant belly and now it's probably going to look like it's been beaten to death with bruising and stuff like that." [1]	High	Canada
	Low perceived efficacy of the treatment and lack of evidence (6,40%)	*"I am very surprised about the low efficacy of the drug and having that low evidence, what is the justification for giving this drug to the patients" [14]*	High	Spain

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Table 3 (continued)

Motive (N, % of preferences)	Category (N, % of participants)	Representative Quote		
		Quote [ID participant]	High/Low Risk of VTE	Location (Canada, Spain)
	Planned delivery and incompatibility with epidural (5, 33%)	*"Having to stop heparin just before delivery"* [8]	High	Spain
		"The epidural is what affects me the most, having to plan and still not being able to get an epidural." [10]	High	Spain
	Concerns with health state major bleeding, and on the unborn (4, 27%)	*"And then that increased risk of having a major bleed. Would be definitely a major risk. And so it was just valuing which was more risky."* [6]	High	Canada
		"Seeing that it [LMWH] could cause a major bleed and stuff, yea, that's a risk factor for not only me but also my unborn baby." [3]	Low	Canada
	Don't like needles (3, 20%)	*"Sticking myself with a needle every day does not sound particularly fun at all"* [6]	High	Canada
	Needing help to administer the injections (2, 13%)	*"Puncturing me every day, the puncture, the schedules, having to depend on someone as in my case to administer it to me"* [15]	High	Spain
Purpose (17, 10%)	*Risk avoidance (6,40%)*	*"Because I know that by taking it I am avoiding a risk, that no one can assure you if it is going to give you a VTE or not, but at least I am already more careful."* [8]	High	Spain
		"Just knowing that it will have a very low likelihood of having a major bleed. Because I was already pretty confident knowing that I would take it for the DVTs but the bleeding part I was a little concerned with." [2]	High	Canada
		"So, I would like to minimize the risk of death as much as possible for 9 months." [1]	High	Canada
		"For me, being a mom, knowing that there are risks to where my clots are placed. Just for me, being a mom and being healthy for my kids was the main factor. I would rather just be on the injections throughout my pregnancy and go through that than risk having complications, having a child. Possibly losing my life or the baby's life in all honesty. Making that decision." [4]	High	Canada
	Peace of mind (4, 27%)	*"For me it gives me more peace of mind to put it on, because even if I have to prick myself every day, I stay calmer that way"* [14]	High	Spain

The fourth action was related to the burden of decision-making. Participants expressed frustration at the added responsibility of having to make yet another decision (regarding thromboprophylaxis) during pregnancy, alongside numerous other essential decisions [P6].

Scene

Scene preferences were the most prominent [43] and were reported by most of the participants [14]. This motive yielded five different contextual conditions.

The most predominant contextual condition reported by most participants, involved their previous personal experience of thrombosis and/or using heparin. The majority expressed a desire to take preventive LMWH during their next pregnancy, driven by the fear and anxiety surrounding their previous VTE [P8] [P14]. One participant showed some reluctance to use LMWH because of the daily needle pricks and the small absolute preventive benefits of the drug; however, due to their previous experience using LMWH and their ability to integrate it into their routine, that participant still expressed a desire to take injections rather than take no action [P15].

The second contextual condition is related to the sources of anxiety and fear about the potential clinical outcomes, leading them to prefer prophylaxis with LMWH. The majority expressed fear of experiencing

a new VTE event, with pulmonary embolism being the worst health case [P14]. Two participants, however, were very concerned about how LMWH would affect their baby [P5]. Other sources of anxiety were the high level of uncertainty around the effects of the drug, not knowing the right moment to initiate LWMH, and that being pregnant already involves many other uncertainties [P1].

The third contextual condition was related to some participants' personal disposition to risk aversion. All these participants preferred to avoid the anxiety caused by waiting and 'not doing anything' by proactively using LMWH [P1].

The fourth contextual condition was related to being pregnant or planning a pregnancy. Participants who were not currently pregnant at the time of decision-making (when the intervention was delivered), reported being uncertain about what decision to make, and expressed that they would probably have a different perspective (or will need to reassess their decision-making) once they are actually pregnant [P12].

The fifth contextual condition was related to participants' access to health care. Some shed light on this by emphasizing their access to essential resources and the possibility of receiving routine health check-ups. The availability of these health care resources played a significant role in influencing their decisions [P12] [P6].

Agent

The motive of agent (i.e., a person or entity involved in the decision) was as prominent as scene (45 preferences) and was reported by all 15 participants. This motive contained three types of influencing people.

The category was related to the level of engagement participants desired when making decisions about their health. Eight participants preferred valuing clinicians' expertise while wanting to search for information to better understand the risks and benefits of available alternatives. This dual approach reflects the participants' trust in their clinician's judgment while also taking ownership of their health choices by incorporating their own priorities[P10]. Six participants reported preferring a passive role, entrusting their clinician to make decisions regarding their treatment. However, all six emphasized their desire to remain informed about the best alternatives available and the reasons behind the recommended course of action [P14]. Only one participant reported preferring active involvement in the decision-making process, although she also listened to her clinicians' recommendation [P11].

The second category was related to those that acted as decision-makers, i.e. who, other than the patient, were involved in the decision. Among participants, the majority reported that the decision was primarily made

between them and their clinician. The majority of these participants felt supported by their clinician[P6] while fewer participants reported some degree of conflict with their clinician [P12]. Some participants also reported involving a family member, typically their partner, as a decision-maker in the process [P15].

The third category was related to the impact of other people's experiences on the participants' preferences. Some participants reported that the experience of a family member or peers (individuals who have used preventive LMWH in their pregnancy) was important to them. Learning about other patients' experiences helped them know what to expect, and ultimately affected their final decision [P14] [P2].

Agency

The agency preferences refer to the medication itself (preferences towards daily injections) and preferences were classified into two attributes: 1) benefits and 2) drawbacks of daily injections with LMWH.

The most reported benefit associated with daily use of LMWH was that 'LMWH prevents experiencing a VTE event' [P6]. Other benefits were: 'No harm for the baby' [P2]; having 'more regular check-ups of their pregnancy' [P13] [P10]; 'perception of low bleeding risk'[P2]; 'perception that LMWH has the effect to prevent miscarriage' [P9]; and, 'can stop the medication immediately'[P11].

In contrast, these participants identified six barriers that negatively influenced their decision to use LMWH daily during pregnancy. These included: 'scheduling injections' being the most prominent [P12], followed by: 'pain, bruising and aesthetics' [P9] [P1]; 'low perceived efficacy of the treatment and low quality of the evidence for recommending its use' [P14]; 'planned delivery and concerns regarding the timing of epidural analgesia' [P8] [P10], 'concerns with bleeding, and perception of risk to the unborn child' [P6] [P3], 'not liking needles' [P6], and 'needing help to administer the injections' [P15].

Although actions were involved in this agency motive, they can be differentiated from the act motive as it doesn't refer to actions regarding the *decision* of using anticoagulation treatment vs. other alternatives, but on *attributes* of the LMWH medication itself.

Purpose

For purpose, 17 preferences were collected, making this motive the least prominent. Half of the participants clearly expressed a motive for their final goal of the decision of taking LMWH during pregnancy. The most reported preference for this motive was risk avoidance by taking LMWH; participants reported their main goal was to avoid the risk of another VTE event during pregnancy [P8], [P2]). Other participants reported that their

goal was to avoid the risk of death [P1]. Few participants reported that their main goal was to be a mother [P4]. The second preference was peace of mind. Some participants expressed that taking LMWH gives them peace of mind and makes them feel they are doing something to prevent the risk [P14].

Table 4 summarizes the findings described previously for each of Burke's pentad motives.

Mixed-methods integration data
Sociodemographic and clinical variables for each of Burke's pentad of motives
For each of the participant's sociodemographic and clinical variables, we reported the number of preferences for each of Burke's pentad motives (see Table S1 in Supplementary Material 2). We observed higher frequency of preferences among participants with higher education level, not pregnant at the moment of the decision-making, at higher risk of recurrent VTE, whose previous event was DVT, and from Spain vs Canada. However, no significant differences were observed in these associations.

Health states with Burke's pentad of motives
We integrated the results from the health state preference elicitation exercises with the preferences categorized in Burke's pentad of motives and represented the findings using a side-by-side comparison (Table 5).

The health state "using daily injections of LMWH" was the closest to the best health state- 'healthy pregnancy' according to the rank ordering and VAS exercise, and was the health state that showed highest utility value. The motives were concordant with these ratings except for agent and agency preferences. Discordant agent preferences were related to the experience of others making them fear having to use daily injections (e.g. one participant that rated daily injections with LMWH as the best health state also said "*the experience of a colleague of mine that had many inconveniences. She was terrified of sticking (a needle) in her pregnant gut*" [P12]). Discordant agency preferences included participants reporting more drawbacks than benefits of using daily injections, suggesting their experience was further from having a 'healthy pregnancy' ("*To be puncturing every day, also puncturing to puncture, because the effect is not much*" [P13].

The health state 'experiencing DVT in pregnancy' showed the second closest to 'healthy pregnancy' for the rank ordering and VAS exercise and second highest utility value. All the motives were concordant with this rating; for example, 'scene' preferences reported that participants had more fear of experiencing bleeding and a pulmonary embolism than experiencing DVT. Similarly, participants reported the 'purpose' of having 'peace of mind' while using LMWH rather than risking DVT ("*For me, it gives me more peace of mind to put it on, because even if I have to prick myself every day, I stay calmer that*

Table 4 Summary of the main categories of each of Burke's pentad motives

Burke's pentad Motives	Main categories
Act	• To gather information from clinician on: benefits and risks of taking LMWH, how to administer daily injections; effects of the drug; and, when is the best time in pregnancy of administration of LMWH • To accept their situation wherein taking LWMH is what is expected • To consider other options first (oral medications, monitoring through ultrasounds, or improving lifestyle behaviors) • Frustration at having to may yet another decision (regarding thromboprophylaxis) during pregnancy, alongside numerous other essential decisions
Scene	• Their previous experience of experiencing a clot was so traumatic that women preferred taking LMWH • It is a decision that makes women anxious specially in relation to the fear of clot and harms to the baby • Personal disposition to risk aversion makes women choose to take LMWH • Being pregnant or not may vary their final decision towards taking or not taking LMWH during pregnancy • Access to health care contributes to the decision-making process
Agent	• Women prefer SDM involvement between them and their clinician • The decision-makers in this process are mainly clinicians and patients, although family members including their significant others may also have an important role in making a decision • Other people's experiences (peers) were informative to women in knowing what to expect
Agency	• The main benefit of LMWH medication is its capacity to prevent a VTE event • The main drawbacks of LMWH medication are: to schedule injections; pain, bruising and aesthetics; having to have a planned delivery and use of regional analgesia/ anaesthesia; low perceived efficacy of the medication and low quality of the evidence for recommending its use; concerns with bleeding and perceived harmful effects on the unborn child; not liking needles; and, needing help from other to administer the drug
Purpose	• Risk avoidance of a VTE event and/or death • Peace of mind

Table 5 Side-by side comparison between health states (quantitative data) and Burke's pentad of motives (qualitative data)

Health state	Burke's Motive		Concordant/ Discordant: explanation
Using daily injections of LMWH during pregnancy • Rank ordering (1–4) = 1 • VAS mean (SD) = 75.07 (21.68) • SG utility value = 0.893	Act	■ Acceptance of their situation	Concordant
	Scene	■ Previous experiences make women prefer taking LMWH for routine thromboprophy-laxis ■ Lack of access to health care makes LMWH the most feasible option	Concordant
	Agent	■ Experience of other women using LMWH during pregnancy	Discordant: Bad experience of other women using LMWH
	Agency	■ Benefits of the medication: Can stop using it immediately when needed and have more monitoring during their pregnancy ■ Drawbacks of the medication: Scheduling injections, pain, bruising and aesthetics, low perceived efficacy of LMWH and low evi-dence, planned delivery and incompatibility with epidural, don´t liking needles and need-ing help to administer the drug	Discordant: Many drawbacks of taking daily injections
	Purpose	■ Give women peace of mind doing some-thing	Concordant
Experiencing DVT in pregnancy • Rank ordering (1–4) = 2 • VAS mean (SD) = 40.40 (26.57) • SG utility value = 0.871	Act	■ Acceptance of their situation	Concordant
	Scene	■ Previous experience makes them not want-ing to go through the same situation ■ Anxiety towards the decision ■ Personal disposition to risk aversion	Concordant
	Agent	■ None reported	Not applicable
	Agency	■ Benefits of the medication: Prevents experiencing a clot	Concordant
	Purpose	■ Peace of mind: doing something to pre-vent VTE ■ Risk avoidance of VTE in their leg	Concordant
Experiencing a major bleeding during deliv-ery • Rank ordering (1–4) = 3 • VAS mean (SD) = 39 (20.76) • SG utility value = 0.833	Act	■ None reported	Not applicable
	Scene	■ None reported	Not applicable
	Agent	■ Experience of other women using LMWH during pregnancy	Concordant
	Agency	■ Benefits of the medication: Low risk of bleeding ■ Drawbacks of the medication: Having risk of major bleeding	Concordant and discordant (perceived low risk of bleeding as a benefit of the medication)
	Purpose	■ None reported	Not applicable
Experiencing pulmonary embolism in preg-nancy • Rank ordering (1–4) = 4 • VAS mean (SD) = 26.73 (14.59) • SG utility value = 0.823	Act	■ Acceptance of their situation	Concordant
	Scene	■ Previous experience makes them not want-ing to go through the same situation ■ Anxiety towards the decision ■ Personal disposition to risk aversion	Concordant
	Agent	■ None reported	Concordant
	Agency	■ Benefits of the medication: Prevents experiencing a clot	Concordant
	Purpose	■ Peace of mind: doing something to pre-vent VTE ■ Risk avoidance of VTE in their leg	Concordant

way" [P14]). There were no 'agent' motives reported for this health state.

For the health state 'experiencing a major bleeding dur-ing delivery' there were few motives specifically address-ing bleeding that would justify the ratings for this health state (third in the rank order and VAS, and second lowest utility value. ' Agent' preferences reported how the expe-rience of family members experiencing major obstetrical bleeding led them to decline LMWH. Preferences from the motive 'agency' showed discordant arguments: while

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some participants reported that they perceived there was a low risk of bleeding, other women were concerned about LMWH prophylaxis causing bleeding.

For the health state 'Experiencing pulmonary embolism in pregnancy' the rating was closest to death according to the rank order and VAS exercises, and presented the lowest utility value. All the motives were concordant with this rating. In particular, the 'scene' preferences revealed a stronger desire to use LMWH since experiencing pulmonary embolism was a very traumatic situation that participants do not want to go through again. Similarly, they reported as a 'purpose' to avoid risk of death, showing a strong agreement with the scores (*"for me it was a very traumatic event, another person who has had the clot in the leg would be less scared, but in my case it was in the lung, I could have died"* [P14]. There were no 'agent' motives reported for this health state.

Discussion

In our analysis, we report the preferences of participants deciding upon the use of LMWH prophylaxis during pregnancy, collected by two different methodologies: quantitatively, we collected value scores for four different health states (i.e. main clinical outcomes) obtained through value elicitation exercises; and, qualitatively we obtained preferences reported in semi-structured interviews and categorized them, using Burke's pentad of motives framework, which uses five different categories (motives) to represent preferences (factors influencing patients' decision-making).

Value elicitation exercises reported that daily injections of LMWH was the health state reported as being closest to a 'healthy pregnancy', followed by the health state experiencing DVT. Pulmonary embolism or major obstetrical bleeding were considered the worst health states (closest to 'death'). Despite our small sample size, statistical differences were observed between the exercise scores and some socioeconomic and clinical variables.

We collected preferences using qualitative methods [8, 22, 30, 35, 36], and categorized them using Burke's pentad of motives framework [24]. This methodology has been used previously [18, 25], for example, to categorize attributes of care plans that make sense intellectually, emotionally, and practically to patients with atrial fibrillation weighing anticoagulation options [18].

" Act" was one of the least reported motives. The actions participants had to take to be able to make a decision were typically regarding the need for information gathering from their clinicians prior to making a final decision. Other authors have also reported that patients taking the right steps, in the correct sequence, at the right time, leads to high quality decisions [18]. The act of acceptance of their situation was another theme

reported; this has also been noted by other authors where it was found that patients felt as if they were responding to their situation by taking action with daily LMWH injections, and acknowledged that by doing something, this helped them regain hope and decrease anxiety [19].

The "scene" motive was the most reported, and contained individual considerations (as personal experiences) as well as broader contextual factors (such as access to healthcare). Although it is widely recognized that effective clinical practice requires attending to the circumstances and needs of individual patients—'the scene'—these are rarely assessed [18, 37]. What are, for instance, the consequences of prescribing LMWH to a patient that cannot afford this medication? A patient-led decision-making experience [19] contributes to making sense of the plan, and speaks to the importance of being aware of the patient's human situation, beyond pathophysiological derangements, to include the patient's personal and social condition [18].

The "agent" motive revealed that the majority of participants expressed a desire for a shared decision-making process with their clinician. The traditional paternalistic model of medical decision-making, in which doctors make decisions on behalf of their patients, has increasingly come to be seen as outdated [38], and using a shared decision-making approach is being promoted especially when dealing with preference-sensitive decisions. Patients want to be involved in the decision, and health professionals describe their role as providing patients with information or helping to explain their situation, while leaving the final treatment decision "up to the patient" [19, 30]. Participants also described other decision-makers that influence their medical decisions; for example, family members such as significant others. Similarly, in another study, the influence of family members on the decision was reported: the husband of one of the participants was worried about the level of risk, which influenced the woman to be more distressed with the decision [19].

In the " Agency" motive we found that the main benefit of LMWH was its ability to prevent thrombosis. However, many drawbacks were reported related to practical issues of the daily injections, such as scheduling injections. The drawbacks being more prominent than the benefits does not necessarily mean that the balance between risks and benefits of using LMWH during pregnancy would tip toward not using LMWH, but it is something that needs to be addressed by health professionals. This could be the reason why we observed statistical differences between the number of agency preferences and participant country (being higher in Spain than in Canada); e.g. those in Spain reported not having sufficient information from their clinicians on how to administer LMWH. Hence,

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practical issues of the treatment options contribute to sense-making and confirm the importance of including this information in discussions about options. Heen et al. [39] showed that adding practical issues systematically to evidence summaries is feasible, can inform guidelines and tools for shared decision making, and may improve patient-centered care. Furthermore, discussing the benefits and drawback perceptions of the medication can support clinicians clarify misconceptions around the medication such as the benefit of LMWH to prevent miscarriages [40].

In general, participants did not frequently express clear statements on their goals of the decision, i.e. their purpose. This motive speaks to the importance of discussing what the options can accomplish in relation to the goals and priorities of each patient, and by doing so, Tinetti et al. suggests that it can reduce treatment burden and unwanted health care [41].

In our mixed-methods findings, we observed that most Burke's motives were concordant with the value elicitation exercises results. This was useful to have more detail and expand on the health states scoring approach (value elicitation exercises). For example, daily injections of LMWH is closest to having a 'healthy pregnancy' because participants accepted that it is what they have to do in this situation (act), and because in their previous experience, they learned how to make injections less painful and cause less bruises (scene). Furthermore, scene preferences reported participants have more fear of experiencing a pulmonary embolism than any of the other health states, while the purpose of avoiding this risk by taking preventive LMWH produces 'peace of mind'.

However, there were also some disagreements between the quantitative and qualitative datasets. One was regarding agent preferences where other individuals' traumatic experiences of using daily injections negatively influenced participants in deciding whether to take LMWH, while in the value elicitation exercises, they rated using daily LMWH as the best health state. Agent preferences were scarce to help explain or give details on the scores given in the value elicitation exercises. Some studies [42] include peer-to-peer experiences in the health states information to support women in gaining knowledge about their situation and knowing what to expect. Online patient forums have also helped participants to both find and provide information and practical advice on what to expect [43].

The other motive in disagreement was agency. It was surprising to see a substantial variety of drawbacks of LMWH considering the high scores for this health state in the quantitative data. However, it is possible that although a variety of drawbacks were reported, they may not be highly impactful in the final decision, but to the need of having sufficient information; this is explained by the overlap between act and agency motives regarding the drawbacks of daily injections of LMWH which highlights the need of patients to have sufficient information [10, 38, 39, 44] that goes beyond the clinical efficacy of the drug and contemplate other attributes of how the treatment would fit into their day-to-day life [18]. Despite the high score relative to the other health states, the VAS result was 0.75 and the SG was 0.893, meaning that taking LMWH presents a significant burden when compared with other treatments, such as taking daily aspirin, for example, which typically has a utility value very close to 1.0 [45].

We identified almost no Burke's motives preferences for the health state 'experiencing major bleeding during pregnancy'. Many participants didn't know what to expect, none of them had a previous experience of bleeding, and based their knowledge on other people's experience. In addition, they were concerned with having to stop medication (knowing when is the right moment) to avoid bleeding and have a planned delivery. The evidence around this clinical outcome is scarce [6, 46], including when using LMWH prophylaxis [47]. In fact, in a case–control study comparing bleeding complications in pregnant patients treated with LMWH to untreated controls, there were no significant differences [46]. For this health state, the differences in risk perception and how this is not just a low or high-risk issue, but what "matters" most for them, even if it is low, is more evident. In line with other studies, participants were more concerned about knowing whether they will be able to access neuraxial anesthesia, and/or whether they will have to plan their delivery [13, 19, 48].

Even when provided with identical descriptions of the health state being evaluated, such descriptions are necessarily incomplete, and patients are likely to fill in the blanks idiosyncratically, with information based on their own personal experiences or stereotypes, [49] as we captured with Burke's pentad or motives.

Strengths and limitations

The mixed-method convergent approach that we followed in this secondary analysis provided a deeper understanding of individual preferences on thromboprophylaxis in pregnancy. While value elicitation exercises (scoring health states) are well accepted [30, 50, 51], they can, in some instances, be imprecise for people's lack of trade-off experience [52]. VAS, compared with SG, appeared to provide more granularity on differences in scores for health states. In our previous work [30] perspectives on the usefulness of each of the value elicitation exercises were reported, showing that among the three exercises, the SG exercise elicited the most

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diverse reactions from participants. Some reported difficulty understanding how to complete the exercise, and reported that having death as an anchor in the exercises was scary, or was not something they were willing to trade with; in contrast, some participants stated that they found the SG to be the most useful of the three exercises.

Qualitative methods, as we showed in our study, help give details on nuances (like individual risk aversion) and assess aspects not defined in the health states (e.g., the impact that other people have on the decision-making process (agent) or, the impact of previous experience with the clinical outcome (scene)). Hence, it was a strength in our study to follow a mixed-methods study design to investigate complex health-related topics using meaningful integration of qualitative and quantitative data [53, 54].

This secondary analysis had a small sample size, making it difficult to observe significant differences which affects the extent to which our results are generalizable to the population with varying clinical and demographic data. Furthermore, the qualitative categorization of the data for quantitative comparisons of the frequency of motives used, could erroneously endorse a motive as important. In other words, an important limitation of the quantitative analysis is that multiple stated motives may be collectively less important than one motive that may be the main driver of the decision. The use of Burke's pentad framework could have been improved by additionally identifying expressions representing importance on decision making (like "I worry about" vs. "I'm not worried about"); therefore, video coding of the clinical encounter, may reflect better (through non-verbal expressions) the importance and effect of factors in decision-making [55].

Implications for practice and research

Although the field of patient preference research is growing, how to retrieve and classify patient preferences continues to be understudied [44, 56, 57], including in pregnant populations [8].

The main contribution of this secondary analysis is to determine values and preferences through multiple methods, which may allow clinicians a comprehensive understanding of what factors affect patients' decision-making and support a SDM that is meaningful and makes sense to the patient. The clinician during consultation, in a SDM atmosphere, should follow these steps to determine their patient's preferences:

- Value elicitation exercises using the main clinical outcomes (health states) descriptions, are useful to help patients know about the risks and benefits of options, and also helps patients feel more prepared for future discussions with their health professional [10, 30]. It

is recommended that patients and clinicians navigate the exercises together, to ensure a shared decision-making approach [10, 18, 44]. Such an approach to eliciting patient preferences is an essential component of patient decision aids [7, 9, 17].

- Understanding and using Burke's pentad of motives in clinical practice can help clinicians see the full picture of what patient preferences are affecting the decision and be able to address them during consultations [18, 25]. However, listening intently to gather this type of information during patient visits can be challenging in time-limited consultations [58] and finding ways to gather it for clinical use without interrupting the visit should be the subject of further investigation.

- Clinical practice should draw attention to moving from paternalistic approaches to informed decisions and shared decision-making approaches, empowering patients to feel and be involved in the decision-making process [38, 57, 59].

Conclusions

People at risk of experiencing a VTE during pregnancy and facing the decision of whether to use prophylactic LMWH don't have a single 'best option'. By using a convergent mixed-method analysis, we were able to understand preferences toward the main clinical outcomes (health states), as it helps to intuitively "tell the whole story" of patient needs, desires, and values, ultimately facilitating discussions between patients and clinicians, promoting a shared decision-making process, and leading patients to make the right decision that fits in their life, and their particular situation.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12959-024-00648-x.

Supplementary Material 1.

Supplementary Material 2.

& editing. MHE: Methodology, Writing – review & editing. SMB: Methodology, Data curation, Investigation, Writing – review & editing. IH: Methodology, Visualization, Writing – review & editing. IP: Methodology, Visualization, Writing – review & editing. SRL: Methodology, Visualization, Writing – review & editing. JAM: Methodology, Visualization, Writing – review & editing. MSA: Methodology, Visualization, Writing – review & editing. RD: Methodology, Visualization, Writing – review & editing. NS: Methodology, Visualization, Writing – review & editing. SMJ: Methodology, Visualization, Writing – review & editing. GG: Methodology, Visualization, Writing – review & editing. LP-P: Conceptualization, Methodology, Data curation, Writing – review & editing, Supervision. PA-C: Conceptualization, Methodology, Data curation, Writing – review & editing, Supervision, Project administration, Funding acquisition. The author(s) read and approved the final manuscript.

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Availability of data and materials
Data is provided within the manuscript or supplementary information files.

Declarations

Ethics approval and consent to participate
This study was approved by the clinical research ethics committee of Hamilton Integrated Research Ethics Board (project id# 5425) and the Hospital de la Santa Creu i Sant Pau (IIBSP-TDC-2018–02). All participants gave written informed consent to participate.

Consent for publication
All participants gave written informed consent for publication.

Competing interests
The authors declare no competing interests.

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