

Article

**Care Pathway of Venous
Thromboembolism (VTE)**DOI: 10.47368/ejhc.2024.301
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CC BY 4.0**A Qualitative Study on the Experiences and
Needs of Patients and Physicians****Liselotte M. van Dijk** , **Linda van Eikenhorst** , **Mattanja Triemstra** 

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Netherlands**Abstract**

Deep vein thrombosis (DVT) and pulmonary embolism (PE) are prevalent diseases associated with high morbidity and mortality. This study aimed to explore the experiences and needs of patients and physicians within the care pathway of DVT and PE. Ensuring care pathways match patients' and physicians' needs, could positively impact therapy adherence and patient satisfaction. Participants were 34 patients and 18 physicians. The qualitative focus groups occurred face-to-face and on an online discussion forum, utilising a predefined topic list. Focus group transcripts were analysed through deductive thematic analysis. Patients and physicians shared similar needs and experiences with information provision and shared decision making. Differences emerged regarding the adequacy of information provided, follow-up and monitoring of residual complaints, and personalised care. Generally, patients expressed higher levels of dissatisfaction compared to physicians. Our findings reveal a disparity between the perceived quality of care by physicians and patients, with patients expressing needs that diverge from physicians' assumptions. Patients need psychological support following DVT and PE, whereas physicians focus on physical recovery. Treatment intensity could be adjusted to align with patients' preferences. These findings highlight the

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potential for optimising care for patients and ensuring better outcomes in the management of DVT and PE.

Keywords

Deep vein thrombosis, pulmonary embolism, patient experiences, physician experiences, focus groups.

Venous thromboembolism (VTE) encompasses two potentially life threatening conditions: deep vein thrombosis (DVT) and pulmonary embolism (PE). Blood clots called DVT often develop in the deep veins of the leg, groin or arm, while PE occurs when DVT clots break off from vein walls and travel through the heart to the pulmonary arteries (Beckman et al., 2010; Goldhaber & Morrison, 2002; Hunter et al., 2017; Wenger et al., 2021).

Many of those who survive a VTE event will be affected for the rest of their lives. Approximately 30% of patients with VTE experience recurrence within 10 years (Heit, 2015; Kyrle et al., 2010). Other long-term consequences of VTE include persistent dyspnoea, bleeding, post-thrombotic syndrome (PTS) and chronic thromboembolic pulmonary hypertension (CTEPH) (Ashrani & Heit, 2009; Galiè et al., 2016; Ghanima et al., 2018; Klok et al., 2014). These outcomes can substantially impact the patient's well-being, physical and psychological health, and everyday functioning.

The incidence of VTE is around one-two cases per 1,000 persons per annum and over 300,000 deaths are estimated per year from VTE in the European Union (Cohen et al., 2007; Members et al., 2008). In 2018, hospital treatment for VTE was administered to nearly 37,000 patients in the Netherlands, which accounts for 0.2% of the entire population. Among these patients, over 18,000 individuals were diagnosed with a PE, among other related conditions (Zorginstituut Nederland, 2021). Strong risk factors for the occurrence of VTE are older age, obesity, heart failure, cancer, surgery, immobilisation and pregnancy (Andersen et al., 1998; Januel et al., 2012; Raskob et al., 2014).

As with other care processes, patient involvement is of importance for patients with VTE for several reasons. Firstly, the treatment objective for most patients dealing with chronic diseases, such as VTE, encompasses adequate symptom control and being able to live with the condition in acceptable ways (Montori et al., 2006). To attain this objective, patients play a crucial role in managing their treatment, monitoring symptoms, and making decisions about their lifestyle (Montori et al., 2006). Given the limited recommendations concerning the treatment of residual physical and psychiatric complaints, patients have an important role in expressing their preferences (Nederlands Huisartsen Genootschap, 2017; Van Daltsen, 2020). Secondly, shared decision making (SDM) should be integral to discussing treatment options. SDM is an approach where clinicians and patients work together to understand and address the patient's unique situation (Elwyn et al., 2010; Hargraves et al., 2016). Central components of SDM in chronic healthcare include building a strong patient-provider relationship, and emphasising information exchange, choice deliberation and decision-making (Montori et al., 2006). The recommended treatment for DVT and PE consists of anticoagulants supplemented, if necessary, by compression therapy (Nederlands Huisartsen Genootschap, 2017; Nederlandse Internisten Vereniging, 2020). For long-term use of anticoagulants, the guidelines recommend (yearly) evaluations to assess bleeding risks (Nederlandse Internisten Vereniging, 2020; Van Daltsen, 2020). Clinicians and patients should jointly decide whether to continue with

anticoagulation therapy after 3-6 months. This decision-making process involves weighing the risks of recurrent VTE if anticoagulation is discontinued against major bleeding if anticoagulation is continued (De Winter et al., 2022; Zorginstituut Nederland, 2019). In the Netherlands, a decision aid is accessible for managing DVT and PE (NIV & De Hart&Vaatgroep, 2017). This tool facilitates discussions between doctors and patients, enabling them to compare treatment options and collectively arrive at a well-informed decision that aligns with the patient's needs (Patiëntenfederatie Nederland, 2017). Despite its promise, SDM has been difficult to implement in practice (Joseph-Williams et al., 2014; Zeuner et al., 2015). Using information from patient reported outcome measures (PROMs) fosters improved communication between healthcare providers and patients, potentially enhancing SDM and subsequently leading to higher patient satisfaction (Black, 2013; Chen et al., 2013; Valderas et al., 2008).

Earlier studies explored patients' experiences in several VTE subpopulations, including women with pregnancy-related venous thrombosis, patients with cancer-associated thrombosis, and adolescents and young adults with VTE (Benelhaj et al., 2018; Gee et al., 2019; Højen et al., 2016). How physicians evaluate the overall diagnostic and treatment processes remains uncertain. Research comparing patient and physician experiences in several health care domains showed unique perspectives specific to the role of being a patient or physician (Gill et al., 2014; Ploeg et al., 2017; Yen et al., 2011). Assessing whether their experiences are comparable may help to better adjust treatment plans to their preferences and needs (Nelson et al., 2015). This may positively affect therapy adherence and patient satisfaction with care. Therefore, the aim of this study was to explore the experiences and needs of patients and physicians with the care pathway of DVT and PE.

Methods

Design

In February and March 2020, nine qualitative focus groups were conducted to explore the study aim. Focus groups were preferred over individual interviews because of their capacity to foster participant interaction, resulting in a broader collection of views and ideas compared to individual interviews (Kitzinger, 1995; Zeuner et al., 2015). Patient focus groups took place face-to-face and on an online discussion forum. All physician focus groups took place on the online forum. The study was reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) (see Appendix A; Tong et al., 2007).

Setting

Face-to-face focus groups involving patients were conducted at Nivel and lasted two hours. Online focus groups were conducted separately for patients and physicians. We used a digital discussion platform that allowed respondents to anonymously respond to questions. During 10 working days, a total of five main questions and several sub questions were posted on the platform. The asynchronous discussion allowed respondents to read and contribute to the conversation on their own schedules.

Participants

Patients were recruited through several social media channels, including the Facebook group ‘Diagnosis group Thrombosis’ from the Dutch Patient Association, the Dutch Thrombosis Service, and through the advisors from Leiden University Medical Centre involved in this study. Inclusion criteria were patients with verified DVT or PE, who suffered from a DVT or PE 3 months to 5 years ago at the time of inclusion, and with first-time diagnosis given after 2015.

Physicians were recruited through several social media channels, through the advisors from Leiden University Medical Centre, and they were approached by the National Health Care Institute.¹ General practitioners (GPs), internists and pulmonologists were eligible to participate in the study as they are most commonly involved in the care for DVT and PE patients.

Data Collection

Prior to the focus groups, respondents filled out a short questionnaire regarding demographics and illness- and treatment-related questions. One topic list was used for conducting all focus groups (see Table 1 and Appendix B). The topic list was drafted by several project advisors including researchers, physicians and a patient representative and fine-tuned during several sessions within the research team. In each face-to-face focus group, 3-8 patients participated per group aiming to vary in gender, age, diagnosis, time since diagnosis, attending physician and type of treatment. The focus groups were led by a female researcher (LvE/MT) who was an experienced moderator. A second female researcher (LvD) was present to take notes. After the participants introduced themselves, the moderator posed questions on the themes indicated above. The moderator assured all participants were heard, asked for clarification when needed and ensured the participants stayed on topic. The face-to-face focus groups lasted 2 hours.

The focus groups on the online discussion platform lasted two weeks, during which every other working day a new question was posted on the online platform. Participants were notified through e-mail each time a new question was posted, encouraging them to respond and interact with the other participants. On days when no new question was posted, clarifying follow-up questions were posted by the moderator. All participants received a gift voucher and any travel costs were reimbursed.

Data Analysis

Face-to-face focus groups were audiotaped and transcribed verbatim. Answers from the online discussion forum were downloaded as transcripts, which were anonymised if necessary. A

Table 1. Discussed Topics in the Focus Groups

Patient and Physician Focus Groups	Physician Focus Groups Only
Health education	Clinical decision rules
Shared decision-making	Diagnostics of DVT and PE
Patient reported outcome measures (PROMs)	
Compression therapy	
Residual complaints, concerns and fears	
Periodic evaluation and monitoring	

Microsoft Excel spreadsheet was created for analysis based on the topic list used. A priori themes were defined based on the available literature, topic list and input from the research team (deductive). After familiarisation with the data, a coding scheme was developed by the researchers and two researchers coded the transcripts following the principles of thematic analysis as described by Braun & Clarke (2006). The researchers discussed the coded segments and any differences were discussed to reach consensus. The coded segments were analysed, grouped and summarised by overarching concepts. Descriptive statistics (frequencies, percentages, means, and standard deviations) were used for describing participants' characteristics.

Ethical Approval

The study has been assessed by the Medical Ethics Committee of the VU University Medical Centre Amsterdam and they have declared that the study is not subjected to Medical Scientific Research with humans (WMO) and determined that the Medical Research Involving Human Subjects Act does not apply to this study (number 2020.032).

Results

A total of 34 patients participated in three online groups ($n = 11$) and three face-to-face groups ($n = 23$). Most had experienced both DVT and PE (Table 2). Also, 18 physicians (eight GPs, eight internists and two pulmonologists) participated in three online focus groups (Table 3).

Analysis of the interviews led to three main themes: 1) information provision; 2) shared decision making about treatment options; and 3) follow-up and monitoring residual complaints.

Table 2. Characteristics of Patients Who Participated in the Focus Groups

Characteristic	<i>n</i>	%
Sex		
Male	3	9
Female	30	88
Diagnosis		
DVT	6	18
PE	13	38
DVT and PE	14	41
Educational level ^a		
Low	0	0
Intermediate	12	36
High	21	64
	Median (IQR)	Range
Age in years ($n = 33$)	48 (12)	28-66

Note. 34 patients participated in the focus groups, but data are missing for 1 patient who did not submit their questionnaire. ^a Low: Primary education, Intermediate: Middle secondary education (mavo), middle vocational education (mbo), higher secondary education (havo), pre-university education (vwo); High: University education (wo), higher vocational education (hbo).

Table 3. Characteristics of Physicians Who Participated in the Focus Groups

Characteristic	<i>n</i>	%
Sex		
Male	7	39
Female	6	33
Medical specialty		
General practitioner	8	44
Internist	8	44
Pulmonologist	2	11
	<u>Median (IQR)</u>	<u>Range</u>
Age in years	39 (9)	34-62
	<u>Mean (SD)</u>	<u>Range</u>
Work experience (in years)	9 (8.2)	1-27
Number of patients with DVT/LE each month in own practice	3.3 (3.6)	0.25-19

Note. 18 physicians participated in the focus groups, but data are missing for 5 physicians who did not submit their questionnaire.

Theme 1: Information Provision

Patients obtained information from different sources at several moments in their care; physicians during hospital admission or at the emergency department, medical specialists (e.g. internists, pulmonologists, gynaecologists, vascular surgeons) during check-ups, and their general practitioner (GP). Information was mainly provided verbally and sometimes combined with an information leaflet. Some patients expressed dissatisfaction with the provided information, due to unmet information needs and overly generalised information. While some patients experienced information overload during the diagnosis process, others perceived a shortage of information and were compelled to search for additional insights to comprehend their diagnosis. Consequently, they consulted social media/fora, scientific literature and their electronic health record. Patients were often too overwhelmed to ask questions during the diagnosis and examination process. Follow-up consults allowed them to prepare their questions in advance, but this did not always result in receiving satisfying answers to their remaining questions.

According to patients, patient-physician communication could be improved by: tailoring information to the patient's needs, always combining verbal and written information, drawing up an action plan for discussing treatment, and appointing a healthcare professional as case manager. They wanted to be better informed about causes for DVT/PE, prognosis, treatment options (both medication and compression therapy), health education and chances of recurrence. It was also important for them to receive an overview of reliable resources of information, such as information leaflets, educational websites and peer-support groups to access when needed.

Health education could be improved by allowing patients to contribute ideas and involving them in what information is needed, such as this [research], for example. (OFG-1)

Physicians indicated information provision has not been standardised nor is it aligned among healthcare providers, resulting in discrepancies in the frequency, efficacy, and timeliness of information exchange. The information shared often became more extensive over time, after the diagnosis. First, general information about the illness was provided in the hospital. Later on, more elaborate information about prognosis, recurrent DVT/PE and lifestyle education was distributed by other healthcare professionals. They acknowledged that this fragmented method may result in delayed dissemination of crucial information to certain patients.

Physicians' belief that patients were content with the information relayed was found to be inconsistent with patients' viewpoints. In instances where a patient required additional information, physicians would refer them to the website from the Dutch Thrombosis Service or Thuisarts.nl.² In parallel with their patients, physicians acknowledged that asking questions increased over time, after diagnosis. Questioning was frequently influenced by information sourced from their GP or the internet. Physicians said they tailored information to the patient's needs (based on their questions) and abilities, however this was not in line with patients' experiences.

As with all types of information provision, it is important to tailor it to the patient's situation and questions. That is what lacks in general educational materials.
(Medical specialist, OFG-1)

Physicians observed that patients frequently experienced difficulties in comprehending all information shared at discharge or during consults. Consequently, they advised patients to audio record their consults. They said combining verbal and written information will enable patients to access and review the information at their convenience. According to physicians, there is no need to develop new types of educational material. They recommend updating current educational materials to ensure their relevancy, including the incorporation of clarifying images. Revision should be aimed at various educational topics, including those concerning women (breastfeeding, risks of the contraceptive pill and alternative contraceptives), information regarding genetic predisposition, compression therapy and medication adherence and lifestyle education.

Theme 2: Shared Decision Making (SDM) About Treatment Options

The ultimate treatment goal for many patients was full recovery from the DVT/PE, and to minimise activity limitations and painful complaints. A more specific treatment goal included regaining sufficient energy to balance work, social contacts, exercising and household chores. In order to reach these goals, drawing up a fitting and feasible treatment plan is essential. Most patients expressed the importance of being involved in their treatment plan, as treatment affects their body and health, and they know their body best.

It matters to me, because shared decision making can offer a sense of safety.
(OFG-1)

Patients' experiences with SDM varied widely. Some had not been involved in decision making; (dis)continuing anticoagulation and/or compression therapy was their physicians' decision. Others had positive experiences with SDM; physicians valued their needs, shared information about possible treatment options and involved them in the development of a

treatment plan. Some patients were content following their physician's advice, as they relied on their knowledge and found it too difficult to weigh out the risks themselves.

To enable SDM, patients needed open and honest communication with their physician, and accurate information about the illness, recovery process and possible treatment options (including pros and cons). Preferably, physicians provide verbal information during a consult accompanied with written information to consult at a later time. Follow-up consults should focus on evaluating and updating treatment plans to ensure they match the patient's needs. To accurately prepare for this evaluation, patients were willing to fill out a Patient-Reported Outcome Measures (PROM) questionnaire beforehand to assess how they feel about their health status.

I would like to have a consult with a physician at the start of treatment, then after 2 to 3 weeks to discuss the progress, then again after several months, and if necessary at the end of treatment. (OFG-1)

Even though most physicians also agreed upon the importance of SDM to improve patient involvement in their own care, implementation in practice was scarce. During the initial treatment phase, physicians often followed protocols in which shared decision making was limited. SDM with patients mainly occurred as treatment progressed to discuss duration of anticoagulation, (dis)continuing compression therapy and contraception choice. Physicians who carried out SDM, relied on their own knowledge, protocols, peer consults, multidisciplinary consultations and tools or decision aids. In order to enhance patient involvement in the decision making process, physicians acknowledged the importance of sharing sufficient information to make a deliberate decision. Similar to patients, physicians have observed that despite patients having sufficient information, the physician's preference still often holds decisive weight in the choice of treatment.

To be able to engage in more SDM, physicians suggested several improvements. Increasing consultation time and knowledge about SDM methods were identified as crucial elements. Decision aids were noted to be important tools in supporting SDM; however, there is room for improvement in illustrating the advantages and disadvantages of each treatment option, while also taking into consideration the patient's personal situation. Physicians have emphasised the need for better patient education, suggesting that hospitals should provide updated educational materials to prepare patients for their next appointment.

Theme 3: Follow-Up and Monitoring Residual Complaints

The frequency of post-treatment consultations, as well as the specific topics discussed with either a hospital medical specialist or GP, exhibited considerable variation across patients. While some patients were satisfied with the aftercare they received, others perceived it as limited, leaving them with a sense of unfulfilled needs. The latter group reported insufficient discussion on residual complaints that impeded their daily functioning, causing both physical (fatigue, pain) and psychological (despondence, anxiety, and insecurity) disturbances. These long-term complaints had a notable impact on the patients' overall health status.

I personally think there is no aftercare. You have an appointment after three months, but by then three months have already passed and in the meantime, you have to figure everything out by yourself. All the while a lot happens to you, both physically and mentally. (FFG-1)

Most patients expressed a need for frequent follow-up consults shortly after diagnosis, which could be reduced over time. They wanted guidance in handling insecurities and fear of recurrence, information about lifestyle education to monitor residual complaints, and to be able to ask questions. Generally, they wanted reassurance that their recovery was progressing well and they did not have any underlying conditions. A sense of security could also be provided by having a contact person to turn to for questions. A preferred healthcare professional for check-ups was not mentioned, as long as the professional in question has adequate knowledge, tailors the check-up to their needs and shows empathy.

Overall, physicians were more satisfied with the follow-up conducted than patients were. Check-ups and periodic evaluations after PE took place with pulmonologists at the hospital. Follow-up after DVT varied; check-ups were mostly conducted by internists or haematologists in secondary care. Check-up frequency varied based on severity, complexity and type of complaints. Physicians said they discussed the following topics during periodic evaluations: course of treatment, patient's physical condition, fatigue and dyspnoea, complaints of the leg or lungs, medication adherence and use of compression therapy, and risk factors and lifestyle education. Contrary to patients' wishes, physicians did not acknowledge the importance of monitoring psychological complaints after a DT/PE.

Improvement suggestions from physicians deviated greatly from those made by patients. According to physicians, follow-up can be improved by increasing the knowledge and expertise of the treating physician, especially about prevention and diagnosis of chronic thromboembolic pulmonary hypertension and post-thrombotic syndrome. Physicians also prefer to have more scientifically based advice and tools to tailor treatment and follow-up to the patient's needs. For patients transferred from the hospital to primary care, GP's wanted to be better informed about diagnosis, information shared with patients, test results, current treatment plan and medication (non-)adherence. Similar to patients, physicians did not mention one preferred healthcare professional to perform check-ups. They said periodic check-ups for uncomplicated DVT could take place in primary care if knowledge about DOACs was increased, while follow-up of patients with PE should remain in hospital. Patients and physicians agreed that it should be clear for everyone involved who is responsible for follow-up care and to whom patients can turn to for questions.

I would prefer if a letter from the hospital states which information has been provided, so I can take this into account. (OFG-4)

Discussion

In this study, we explored the experiences and needs of patients and physicians with the care pathway of deep vein thrombosis (DVT) and pulmonary embolism (PE). We found both contradictions and similarities between their perspectives regarding 'information provision', 'shared decision making', and 'follow up treatment'. Patients' and physicians' information needs and experiences with (a lack of) shared decision making (SDM) were generally the same. Differences occurred regarding their experiences with the information relayed, follow-up and monitoring of residual complaints, and tailoring care to the patient's needs. Comparing their perspectives provided leads for improvement of care for patients with DVT or PE.

Patient and physician perspectives regarding information provision revealed notable differences. Consistent with the findings of Rolving et al. (Rolving et al., 2019), our study

reaffirmed the importance of timely and comprehensive information dissemination for patients diagnosed with DVT and/or PE in enabling them to cope effectively with their conditions. However, patients who expressed dissatisfaction with the information they received, said the information did not meet their expectations. In contrast, physicians were generally unaware of this discontent and believed that the information they provided was satisfactory. Overestimating the degree of personalised care appears to be a common problem among healthcare professionals (Esmaceli et al., 2014). Both patients and physicians agreed that the available educational materials could be improved. They emphasised the importance of information being independent, comprehensible, unambiguous, up-to-date, and easily accessible. Patients specifically recommended a combination of verbal and written information. Moreover, they emphasised the need for individualised approaches, tailoring the timing and amount of information to meet each patient's unique needs.

To achieve this, active involvement of patients in their own care and the promotion of shared decision making (SDM) were identified as crucial. However, patients and physicians acknowledged the current lack of SDM in practice. The extent to which they consider SDM to be possible differs. Although patients believed that their personal treatment goals should guide treatment decisions, physicians saw less possibilities for patient participation when following protocols, particularly at the initiation of treatment. Nonetheless, they acknowledged there is room for SDM later on in the course of treatment, for example when deciding whether to continue or discontinue anticoagulant therapy. Conversation or decision aids can be used more extensively to implement SDM in practice. These tools should contain high quality, comprehensive and up-to-date evidence on the concerning topic (Montori et al., 2013). In the Netherlands, a decision aid is available for the treatment of DVT and PE (NIV & De Hart&Vaatgroep, 2017). However, physicians found this tool to be too concise in its current form.

Patients and physicians recognised the importance of follow-up care and monitoring of residual complaints in the management of DVT and PE. The existing Dutch guidelines lack clear instructions on the frequency and responsibility for conducting such evaluations (Nederlandse Internisten Vereniging, 2020; Van Daltsen, 2020). This lack of clarity could leave more room for tailored care, but this was not the case as both groups found this lack of clarity and continuity undesirable. Physicians expressed uncertainty regarding the healthcare professional who should assume this role, while patients expressed the need for a dedicated point of contact to address their questions and concerns. The importance of having a knowledgeable healthcare professional who can take charge of treatment and provide ongoing support is a common theme in research on post-VTE treatment (Rolving et al., 2019). Physicians and patients have different views on the topics that should be discussed during follow-up visits. While physicians focused primarily on clinical outcomes, patients expressed a desire for guidance in managing residual complaints, addressing uncertainties, and coping with fears. Patients reported a significant impact of VTE on their daily lives, consistent with previous studies highlighting the profound effects of VTE on patients' well-being (Etchegary et al., 2008; Højen et al., 2016; Hunter et al., 2017; Noble et al., 2014). Respondents said VTE was often perceived as a traumatic event, with fear of recurrence causing psychological distress.

Our findings suggest that incorporating patient-reported outcome measures (PROMs) could bridge the gap between these two perspectives. ICHOM (the International Consortium for Health Outcomes Measures), has assembled an international working group to develop a

minimum standard set of PROMs for VTE that are relevant to patients (Gwozdz et al., 2022; ICHOM). By assessing the actual impact of VTE on patients' physical, psychological, and emotional functioning in their daily lives, PROMs can provide physicians with a more realistic understanding of patients' well-being and evolving needs over time. Subsequently, addressing these various health outcomes during follow-up consultations can improve communication and shared decision making regarding the patients' health plans and ongoing needs, thereby promoting a more patient-centred approach to care (Freel et al., 2018; Greenhalgh et al., 2018; Stover et al., 2021; Yang et al., 2018).

To summarise, prioritising patient-centred care has emerged as a key focus in this research. As discussed earlier, involving patients SDM throughout their healthcare journey and incorporating PROMS can boost patient engagement. Additional strategies to enhance patient involvement included offering curated informational resources for patients to educate themselves, recording consultations for reference, and updating educational materials to help patients prepare for upcoming appointments. Availability of updated brochures and care plans has been identified in other studies as facilitating factors to promote patient participation as well (Oxelmark et al., 2018). Other facilitators included presence of a significant other, written communication tools such as care diaries and the use of iPads to document patient information on the electronic health record, and providing sufficient time during consults to answer questions (Cohen & Botti, 2015; Oxelmark et al., 2018; Venedey et al., 2020).

As with all studies, it is important to consider the data within the context of the study limitations. It should be noted that the sample utilised may not be fully representative of all patients and physicians affected by the treatment of DVT and PE. There was a notable overrepresentation of young women with PE, while DVT patients, men, and older patients were somewhat underrepresented. Patients were recruited through Facebook, among other channels. This aligns with earlier studies that revealed that females are more open to finding social support in online communities than do males (Tifferet, 2020). Furthermore, the recruitment of physicians coincided with the emergence of the COVID-19 pandemic emerged in the Netherlands. To ensure the desired inclusion criteria were met, the authors personally invited physicians to participate. This approach may have introduced a potential bias, as the participating physicians could possess higher levels of involvement and experience in the treatment of DVT and PE. Despite these shortcomings, this study was able to reveal discrepancies between care provision/physician perspectives on the one hand and healthcare use/patient perspectives on the other. Furthermore, both groups of respondents proposed recommendations for improvement.

Conclusion

This study explores the experiences and needs of patients and physicians with the care pathway of DVT and PE. Our findings reveal a disparity between the perceived quality of care by physicians and patients, with patients expressing distinct needs that diverge from physicians' assumptions. The profound impact of uncertainty and fears on patients' daily lives underscores a substantial demand for psychological support following DVT and PE, whereas physicians primarily focus on physical recovery aspects. Moreover, our results show the potential for tailored treatment intensity to better align with patients' preferences by implementing more frequent check-ups during the initial recovery period and gradually decreasing them over time.

We also identified potential for a more integrated role of SDM during the patient journey, for instance when drawing up a fitting treatment plan and when deciding whether to continue or discontinue anticoagulant therapy. These findings highlight the potential for optimising the care experience for patients and ensuring better outcomes in the management of DVT and PE. By bridging the gap between physician perceptions and patient needs, we can foster a more patient-centred approach and ensure more effective care provision for individuals affected by DVT and PE.

Notes

1. National Health Care Institute is a public organisation that assesses health care systematically.
2. An independent website for health information, developed and maintained by the Dutch College of GPs.

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Ethical Approval

The study has been assessed by the Medical Ethics Committee of the VU University Medical Centre Amsterdam and they have declared that the study is not subjected to Medical Scientific Research with humans (WMO) and determined that the Medical Research Involving Human Subjects Act does not apply to this study (number 2020.032).

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Conflict of Interest

All authors declare that they have no conflicts of interest.

Supplementary Material

The appendix to this article can be accessed online: <https://doi.org/10.47368/ejhc.2024.301>.

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