

Adolescents' and young adults' life experiences following venous thromboembolism. "It will always lie in wait"

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1 **Title**

2 Adolescents' and young adults' lived experiences following venous thromboembolism. *"It will*
3 *always lie in wait"*

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22 **Running head:** Mental well-being of young VTE patients

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Abstract

Background: Long-term mental well-being of adolescence and young adults diagnosed with venous thromboembolism (VTE) as experienced by the patients has received little attention.

Objectives: The purpose of this study was to explore the essential meaning of adolescents' and young adults' lived experiences following VTE to gain an in-depth understanding of their long-term mental well-being.

Methods: Semi-structured interviews were conducted with 12 Danish patients who were diagnosed with VTE in adolescence or young adulthood. Interviews were analyzed according to a phenomenological hermeneutical approach inspired by the French philosopher Paul Ricœur's theory of interpretation.

Results: Four themes emerged. Participants described an experience of a creeping loss of youth immortality, a perception of being different, to live with a body in a state of alarm, and to feel symptom management insecurity.

Discussion: Mental well-being of adolescence and young adults diagnosed with VTE is negatively impacted in the long-term. Fear of VTE recurrence predominates and is an important source of psychological distress. This study highlights the clinical importance of including the long-term mental well-being in the overall assessment when developing rehabilitations programs for adolescents and young adults diagnosed with VTE.

Keywords

Adolescents; Psychology; Qualitative; Thrombosis; Venous thromboembolism; Young Adult

1 Venous thromboembolism (VTE) that includes deep venous thrombosis and pulmonary
2 embolism is a frequent and potentially lethal disease affecting 1 in 1000 per year (Goldhaber &
3 Bounameaux, 2012). The incidence of VTE increases with age, approximately doubling with
4 each decade. VTE is therefore less common in young age with an incidence rate of 3.2 per 10,000
5 person-years for patients aged <30 years (Martinez, Cohen, Bamber, & Rietbrock, 2014).
6 However, evidence suggests that young VTE patients in particular are at risk of subsequent
7 psychological impairment; in the short term, younger age has been found to be a significant
8 predictor of elevated levels of anxiety and thrombosis worries (Moore, Norman, Harris, &
9 Makris, 2006), and thrombosis patients aged < 34 years reported facing greater psychological
10 impairment than those aged ≥ 34 years (Fiandaca et al., 2006).

11 From a transition theory perspective, adolescent and young adult VTE patients will
12 experience multiple and simultaneous transitions enhancing the risk of a disrupted sense of
13 balance and well-being (Meleis, Sawyer, Im, Hilfinger Messias, & Schumacher, 2000). The
14 developmental transition of adolescence is marked by identity formation and growing
15 independence, and involves many significant biological, psychological and social changes
16 (Sigelman & Rider, 2012). The task of identity formation continues into young adulthood where
17 independence grows stronger and includes transitions marked by intimacy, generativity and
18 career consolidation which today most often continues into the early thirties (Sigelman & Rider,
19 2012). In addition adolescents and young adults face the health-illness transition of VTE
20 involving adaption to the potentially stressful situation (Thompson & Gustafson, 1999). The
21 increased complexity that emerges from multiple transitions enhances vulnerability to distress,
22 confusion and instability (Meleis et al., 2000). Extensive research has accordingly been devoted
23 to this issue with clear evidence produced to substantiate that physical illness in adolescence and
24 young adulthood such as cancer or diabetes can result in significant long-term psychological,

1 emotional and behavioral problems (DeMaso et al., 2009; Skaali et al., 2009; Zoffmann, Vistisen,
2 & Due-Christensen, 2014). The mental well-being of young VTE patients has received less
3 attention, but negative emotions and concerns have been reported to persist over time (Bennett,
4 Patterson, & Noble, 2014; Noble, Lewis, Whithers, Lewis, & Bennett, 2014). Indeed, a
5 substantial excess risk of psychotropic drug purchase has been reported among adolescents and
6 young adults 5 years after a VTE diagnosis when compared to peers (Højen et al., 2015).
7 However adolescent and young adults perceptions of the meaning of having VTE, in relation to
8 long-term mental well-being has been insufficiently explored.

9 **Purpose**

10 Exploring the essential meaning of the lived experiences of adolescents and young adults
11 following VTE could give an in-depth understanding of their long-term mental well-being. Thus,
12 the study addressed the following research question: What is the essential meaning of the lived
13 experiences following VTE in adolescence or young adulthood?

14 **Methods**

15 A qualitative design using a phenomenological hermeneutical approach influenced by the French
16 philosopher Paul Ricœur's theory of interpretation was chosen (Dreyer & Pedersen, 2009;
17 Ricœur, 1973, 1981). According to Ricoeur, interpreting a text means seeing something new in
18 what is already taken for granted and to disclose a sort of being-in-the-world (Ricœur, 1973).
19 Thus, this approach allowed us to gain insight into the essential meaning of adolescents and
20 young adults lived experiences following VTE and thereby an in-depth understanding of their
21 long-term mental well-being. The study design is presented in Figure 1. A two-phase data
22 collection was used to foster familiarity and encourage the participants to talk freely about their
23 experiences, followed by an analysis inspired by Ricœur's theory of interpretation.

1 **Participants**

2 Participants were recruited during either an admission for VTE at a University hospital or a
3 County hospital or an outpatient clinic at a Thrombosis Centre in the North Denmark Region,
4 Denmark. Participants were included during the period November 2012 to June 2013 according
5 to the following inclusion criteria: confirmed VTE diagnosis at admission or previously, aged
6 between 13 and 33 years at VTE diagnosis, and ability to speak and understand Danish.
7 Exclusion criteria were a previous psychiatric diagnosis or treatment for mental health problems.
8 Maximum variation in sampling was sought to gain multiple perspectives and exemplifying
9 complexities to obtain an in-depth understanding of the long-term mental well-being of
10 adolescents and young adults diagnosed with VTE. In addition to nine consecutively included
11 participants, three patients who were known to the Thrombosis Centre prior to the study and had
12 an initial VTE event 4 to 5 years earlier were recruited and purposefully included to ensure
13 maximum variation in experiences related to timespan, duration of anticoagulant treatment and
14 parental status. A health care professional on the ward or at the Thrombosis Centre gave the
15 participants an information letter and they were asked to consider participation in the study. All
16 participants agreed to participate, and the first author contacted them immediately thereafter.

17 **Data collection**

18 Phase 1 of the data collection facilitated the development of interview guides. It consisted of
19 participant observations and informal interviews by the first author during the participants' VTE
20 admission or out-patient visit and focused on the complexities of the issues related to having
21 VTE as seen from the participant's perspective (Hammersley, 2007). Observations were
22 descriptive and lasted between 2 and 9 hours. They included grand tour and mini-tour
23 observations of the hospital setting, the patient, healthcare professionals, relatives,
24 procedures, formal meetings, informal conversations, objects present, actions and events carried

1 out, time spent, the goal trying to be accomplished and feelings expressed (Spradley, 1980). On
2 basis of field notes generated during these observations, both general and specific individual
3 questions were raised and formed the basis of the interview-guides.

4 In phase 2, data were obtained by means of open semi-structured interviews,
5 performed by the first author 6 to 11 months after recruitment of the participants. The interviews
6 were conducted either at the participants' home (9 interviews) or at the hospital (3 interviews),
7 depending on participant preference. All interviews were opened by the question: "Please tell me
8 about your life after you had a blood clot". When needed, elaborating questions were asked, e.g.
9 "You told me it felt strange to be hospitalized because you did not feel truly ill. Could you please
10 elaborate on that?" The interview questions were not established in a fixed sequence but rather as
11 prompts (Hammersley, 2007). The open and flexible approach allowed the interviews to flow in a
12 natural way and ensured rigor in capturing the participants' perspectives by allowing them to
13 speak freely about their life experiences post-VTE. The length of the interviews was guided by
14 the process of saturation to ensure depth of data (O'Reilly & Parker, 2012). Thus, the interviews
15 continued until the narratives became repetitive and no new data was revealed. Interviews lasted
16 between 45 minutes to 1 hour and 28 minutes, and were digitally recorded and transcribed
17 verbatim by the first author directly after they were conducted.

18 **Data analysis**

19 The transcribed interviews were analyzed, influenced by Ricœur's interpretation theory, and
20 consisted of three levels: a naïve reading, a structural analysis and a critical analysis and
21 discussion (Dreyer & Pedersen, 2009; Ricœur, 1973, 1981).

22 The *naïve reading* was the initial grasping of the meaning of the text as a whole. All
23 interviews were read pursuing a general sense of the whole, by being open towards the text and
24 making guesses and presumptions about the meaning.

1 The *structural analysis* was the explanatory stage between the first surface
2 interpretation of the naïve reading and the in-depth interpretation of the critical analysis and
3 discussion. Understanding the text is to follow its movement from sense to reference, from what
4 it says to what it speaks about (Ricœur, 1981). Thus, in the structural analysis the meaningful
5 content and the patterns in the text were extracted by interpreting what the text said across the
6 data (interview quotations); obtaining distance in the interpretation and text structure releasing
7 the text from the original intention and meaning of the interview situation by creating short
8 stories linked to the meaning and understanding of what the text spoke about; and identifying
9 themes relating to both what the text said and what the short stories spoke about (Dreyer &
10 Pedersen, 2009).

11 In the *critical analysis*, the themes identified in the structural analysis were
12 interpreted and discussed in relation to both the short stories and the quotes from the interviews,
13 in a dialectic movement between explanation and comprehension. In the *discussion*, the
14 interpretation of the findings was further substantiated by expanding the dialectic movement
15 between explanation and comprehension, which validates the interpretation through
16 argumentation (Ricœur, 1981). Relevant literature and pre-understanding was therefore used in
17 the discussion to argue in favor of one or several suitable interpretations. Ricœur refers to this as
18 the final act of comprehension - a new sort of being in the world (Ricœur, 1973).

19 The qualitative data analysis software, NVivo (QSR International v.10) was used to
20 organize, retrieve and report the textural data. Conducting the analysis in NVivo allowed a
21 dialectic movement between explaining and comprehension, from *what the text said* (the
22 interview-text as a whole and the quotations) to *what the text spoke about* (themes) and ensured
23 credibility of the findings because the dynamic process of the three interpretation levels could be

1 followed. On all three interpretation levels, analyses and interpretations were discussed by all
2 authors to enhance trustworthiness.

3 **Translation**

4 The study was conducted in Denmark, and translation therefore posed a particular challenge
5 (Regmi, Naidoo, & Pilkington, 2010). To ensure trustworthiness of our findings, interviews were
6 transcribed in Danish and the analysis conducted in Danish before translating the quotations and
7 short stories into English (see Supplementary Table 1 and 2 for Danish stories and quotations).
8 Translation fidelity was sought by determining the context and relevance in discussion between
9 the native Danish and English speaking authors, forward-backward translation and examining the
10 meaning in both source and target language with help from a professor in language and
11 translation revision (Regmi et al., 2010).

12 **Ethical considerations**

13 The North Denmark Region Committee on Health Research Ethics assessed the study and in
14 accordance with Danish law a formal ethics approval was not required. All participants were fully
15 informed about the purpose of the study and informed consent was obtained both verbally and in
16 writing before enrolment. The participants retained the right to withdraw from the study at any
17 point. Authorization by the Danish Data Protection Agency was obtained (File No. 2012-41-
18 1134).

19 **Findings**

20 **Participant characteristics**

21 All 12 eligible participants (9 women 3 men) invited agreed to participate in the study. Patient
22 characteristics are presented in Table 1. Age of the participants at inclusion ranged between 17-
23 33 years. Given the inclusion of participants with VTE recurrence (n = 7) the timespan from first
24 VTE to the semi-structured interviews ranged from 6 months to 13 years. Of the participants, 5

1 were initially diagnosed with VTE in adolescence and 7 were initially diagnosed with VTE in
2 young adulthood. The majority of participants had experienced both DVT and PE (n = 8). Half of
3 the participants lived with a partner, three of whom had children, one third still lived at home and
4 one third lived alone.

5 **The naïve reading**

6 The *naïve* reading gave the initial impression that fear of a recurrent event was prominent in their
7 life after VTE. The participants described an increased vigilance towards pain or other bodily
8 changes to ensure they would recognize symptoms of recurrent VTE. Further, an awareness of “I
9 could have died” was prominent in the narratives. The participants gave a lot of thought to how
10 serious the VTE had been or could have been, although many described the VTE event as not
11 critical. Observing other people’s reaction was an experience worse than having the VTE. It was
12 tough and unpleasant to see relatives sad, scared, and worried, and it made the participants think
13 and reflect. The participants described how they did not consider themselves truly ill. However,
14 at the same time they had to take anticoagulants, had frequent doctors’ visits because of careful
15 and regular monitoring, had to wear compression stockings, had to live with swelling and pain in
16 their leg, as well as alcohol restraint and were unable to participate in certain sporting activities.
17 This affected social- and everyday life, and made them feel different.

18 This initial understanding raised questions about the experienced fear of VTE
19 recurrence, the relationship between the experience of the VTE event and the subsequent
20 reappraisal of the health threat, and about not feeling ill but still experiencing life as being
21 affected by VTE.

22 **Structural analysis**

23 Reading and structuring what was said in the transcribed interviews created meaning of what the
24 text spoke about. The meaning and understanding was captured as a whole and released from the

1 original intention and meaning of the interview situation by creating short stories. The short
2 stories were written in the first-person but captured what the text spoke about across all the 12
3 interviews. The stories – *My life after VTE* are presented in Table 2, with the headlines: Sh** it
4 was a close call, I am not like the others anymore, it is always looming in the background, and I
5 could actually have died of this! Relating to what the short stories spoke about and what the
6 interview text said the following four themes emerged: A creeping loss of youth immortality, the
7 perception of being different, to live with a body in a state of alert, and symptom management
8 insecurity.

9 **Critical analysis**

10 The four identified themes were interpreted in the critical analysis and discussed in relation to the
11 short stories as well as the quotes from the interviews in a dialectic movement between
12 explanation and comprehension.

13 *A creeping loss of youth immortality*

14 The perception of a loss of immortality was prominent in life after VTE. However, this had not
15 been an immediate revelation. The participants described how they had progressively “become
16 aware of how little it takes” and had come to realize “that nothing lasts forever”. At the time of the
17 VTE and during the acute treatment they explained how it had not felt truly critical and how they
18 had not perceived themselves as seriously ill. This included participants who had experienced a
19 near fatal pulmonary embolism. A female participant with a pulmonary embolism described how
20 she had not felt as unwell as she objectively was. It was not until later when she saw her parents’
21 reaction she realized how life-threatening it had been:

22 My mother told me, my face turned blue, and they could see how my body desperately
23 needed oxygen, and this really frightened them. I don’t remember it being that bad, but

1 now afterwards, when you think about it, well, it scares me, because it was probably a
2 closer call than I had thought.

3 The more worried the participants witnessed their parents, their partner, and other relatives, the
4 more it made them think and reflect about the seriousness of this disease. Especially their fathers’
5 reactions made a big impression: “It was really really tough; I am not used to seeing my father cry. He
6 has always been one tough cookie. He never cries. It was very scary to experience.” Thus, the reaction
7 of others was important for the participants’ perception of having VTE and confronted with these
8 reactions their sense of immortality was progressively shattered and mortality became salient. For
9 some this resulted in a late reaction of anxiety and nightmares: “I was scared sh**less and had
10 nightmares, dreamt I burned alive. Well, at that point all the emotional stuff began to emerge, that I
11 actually could have died.” The participants ruminated on what had happened and what could have
12 happened. This psychological aftermath was hard to handle and was described as an “on-going
13 fight”. A female participant explained how she felt she was mentally falling apart having had
14 several anxiety attacks, and how she lacked somebody to talk to about her experience, despite
15 strong support from family and friends. The salience of mortality also made it important for the
16 participants to live life to the fullest. They described how they now felt obligated to accomplish
17 something in life. Thus, for some it had entailed a change in their educational path.

18 ***The perception of being different***

19 In their lives after VTE the feeling of being different was prominent. It was described as being
20 particularly challenging and a cause of distress. A female participant described: “Suddenly I felt
21 different than the others, I think that was hardest, that I suddenly wasn’t like the others anymore”. The
22 participants did not consider themselves ill. However, they perceived themselves to be at lifelong
23 risk of a recurrent event, and described how the medication management, the compression
24 stockings, and physical symptoms related to post thrombotic syndrome had a substantial impact

1 on everyday life. The participants explained how this restricted the ability to feel “normal”.
2 Hence, some described that they felt they had become a different person both mentally and
3 physically.
4 For the participants requiring anticoagulant treatment the experience of being different was
5 widely apparent in social contexts. Attending parties and drinking alcohol was perceived as a
6 central part of the social life of the participants, and restraint from drinking alcohol because of
7 anticoagulant treatment made them feel excluded. “You just feel a little left out when you can’t
8 participate; when you can’t get drunk and be happy in the company of the others, then the party
9 becomes different for you, you’re a part of it, but not in the same way”. They were aware total
10 abstinence from alcohol was not required. However, drinking one or two beers was not perceived
11 as a normal drinking pattern. Thus, this did not allow them to be a genuine part of the social
12 group, and they mostly refrained from drinking alcohol altogether. The participants would try to
13 find alternative strategies to be a normal part of social activities and a genuine part of the social
14 group. One way was to hold a position at the party where alcohol restraint was socially
15 acceptable, for instance being behind the bar. However, peer pressure to drink still occurred and
16 could be hard to handle. Thus, not attending parties was in some cases perceived to be the easiest
17 solution, even though it left them feeling socially excluded (although self-imposed).
18 The participants described not only how they felt different from peers but also how they felt
19 different from other VTE patients. They recognized the general population’s (mis)perception of
20 VTE as a disease occurring only in ‘old’ people. A female participant explained:
21 Most people say that it’s really not what you would expect a girl of your age to go
22 through, and that’s what I think as well. I just got one of the pamphlets again, and all the
23 pictures in it are of somebody walking with a crutch or a walker [...] it makes you think,
24 you are a bit like a loner.

1 Hence, the experience of being different both as a VTE patient and among peers, resulted in the
2 perception of being alone even though the participants emphasized how caring and supportive
3 their relatives and friends were: “I actually feel alone, I know it sounds stupid in a way, I have a nice
4 boyfriend and family, it is just so hard to explain; it’s just, they listen and stuff, but I don’t really feel
5 understood.” Thus, even with strong support from family and friends the participants described
6 being lonely and lacking somebody who truly understood them and their experiences. A few of
7 the participants had by sheer coincidence met another young VTE patient and emphasized how
8 reassuring this had been. This had made them feel less alone and different. “It is reassuring in some
9 way that you are not alone in having experienced this, that somebody else has experienced it and can
10 relate to it.”

11 *To live with a body in a state of alert*

12 Fear of recurrence was a great concern in life after VTE. The participants lived with the
13 uncertainty of if, when, and what would happen if they had another VTE. They described their
14 body as having a flaw. It was their weak link, and the risk of recurrence was thereby perceived as
15 something that would follow them through life; something they would have to learn to live with.
16 “This will stick with me for the rest of my life, like a little cloud that floats in your mind, that is how it is.”
17 Thus, it was a narrative they carried with them and it resurfaced in various situations. When
18 experiencing signs or symptoms they described how their mind was programmed to think it could
19 be VTE. The participants were highly alert of signs and symptoms suggestive of VTE, and found
20 it essential to be able to recognize these. A male participant explained how he had become more
21 aware of his body’s responses:

22 I have become more alert than I used to. I can feel more things now, than I could
23 previously. You take it for granted, how your body works. You don’t think about it. Now I

1 do. I feel everything in my body now. I have to be more alert of what my body does, what
2 it complains about, so I can be more observant next time.

3 Thus, the patients' bodily awareness was heightened, related to the underlying fear of recurrence,
4 and the concomitant fear of a more serious outcome of a possible VTE recurrence. It could come
5 out of the blue and it could be life-threatening. Regardless of the severity or type of VTE the
6 participants thereby described how symptoms that were hard to interpret made them anxious: "If I
7 am in pain and can't understand what is wrong, it really makes me cry, and actually I would say that the
8 physical pain during this has not been the worst, it is the mental pain that came after that was the
9 worst". This was especially troublesome for participants suffering from post-thrombotic
10 syndrome because the related pain and swelling of the leg could be hard to distinguish from
11 symptoms of VTE recurrence.

12 The feeling of uncertainty was enhanced and resurfaced in situations of increased
13 risk of recurrence. It made some of the participants worry about traveling and consider whether
14 they could risk becoming pregnant. Nonetheless, most of the young girls were determined not to
15 let the VTE prevent them from starting a family. A pregnancy did however make the risk of
16 thrombosis highly salient: "I could feel how it kicked me right back into it; I found it to be really, really
17 tough." Thus, a pregnancy, which was expected to be a positive experience became a course of
18 illness. Furthermore, patients described how becoming a parent created a set of new worries. The
19 responsibility for another life led to a stronger fear of recurrence. To relieve the uncertainty of
20 recurrence, it was essential for the participants to be well medicated and to find a cause for the
21 VTE. One participant explained: "If you don't know where it came from you cannot know whether it
22 will come back again." However, even participants who objectively had a clear identified cause
23 related to a transient risk factor described how they were aware that in certain circumstances they
24 would always be at high risk of recurrence. Furthermore, participants explained that being well

1 medicated did not relieve the feeling of uncertainty completely: “Even though I was told, that it
2 can’t happen again as long as I take my medicine, it’s still just not enough. It is the anxiety I think, the
3 fear that this could happen again.” Thus, the feeling of uncertainty was also present among
4 participants who had a clear identified cause and participants who were well medicated. Thus, to
5 be highly alert and to react to signs and symptoms was perceived as important among all
6 participants because of a more or less profound uncertainty and the perception that VTE would
7 always lie in wait.

8 *Symptom management insecurity*

9 Worry and concern that symptoms suggestive of VTE recurrence would be neglected were
10 evident in life after VTE. The participants often had several doctors’ visits before they were
11 initially diagnosed with VTE, resulting in a breach of their trust in doctors and the doctor’s
12 ability to correctly interpret symptoms of VTE: “It was so disturbing how three doctors, as well as my
13 GP more than once, could disregard my signs and symptoms, I didn’t feel I could trust any doctors, and I
14 still don’t.” The breach of trust the delayed diagnosis evoked was for one participant eased by an
15 explanation and conversation with her GP about how difficult it had been to make the VTE
16 diagnosis. Nevertheless, because of an overriding concern that VTE-related issues would be
17 neglected, the necessity of self-reliance was prominent. It was of paramount importance for the
18 participants to be persistent and to be in control of their health. Self-managed anticoagulant
19 treatment, allowing self-testing of INR and adjustment of medication, was described as one
20 possible situation to be in control of: “Suddenly it has become super important to me, that everything
21 is under control, and I am best in control if I control it myself. The control in knowing that I know what it
22 is all about.” However, when the participants experienced symptoms suggestive of VTE their
23 ability to be in control was limited. In this context, they had to rely on the health care system and

1 the doctors to confirm or refute their suspicion. Consequently, the participants used different
2 strategies to make sure they were taken seriously by doctors and that their symptoms were not
3 neglected. They used a form of silent negotiation where they let the doctors examine them and
4 waited until afterwards to explain and emphasize how these symptoms resembled their previous
5 VTE. Others changed their general practitioner: "To make a fresh start". Further, a female
6 participant described how she would exaggerate her symptoms to ensure she would be examined:

7 Sometimes I can hear myself make matters worse, just to make sure they will take a look
8 at me, and to make sure they will listen to me and to what I am telling them. I'd rather
9 they have a look at me and then be sent home with the message that everything seems
10 fine.

11 Thus, the participants would go to great lengths to be examined, because it was of critical
12 importance that concerns would be taken seriously, as they feared VTE recurrence would be
13 fatal. Consequently, the participants had many visits to doctors and hospital readmissions. One
14 participant explained: "I rather they find out nothing is wrong, than something shows up. I would
15 rather be admitted 40 times in one year."

16 **Discussion**

17 We found that adolescent and young adults lived experiences following VTE involved four main
18 themes: a creeping loss of youths' immortality; a perception of being different; having to live
19 with a body in a state of alert; and symptom management insecurity. The interpretation of these
20 findings was further substantiated, by expanding the dialectic movement between explanation
21 and comprehension to gain an in-depth understanding of the mental well-being.

22 Findings revealed that mortality was salient in life after experiencing a VTE,
23 causing distress and anxiety. This had not been an immediate revelation, but a realization
24 connected to their parents' reaction to their VTE. This could be explained by the transactional

1 stress and coping model by Thompson and colleagues which discusses the interconnectedness of
2 adolescent and parent adjustment when adapting to chronic illness (Thompson & Gustafson,
3 1999). The participant's developmental level at VTE diagnosis, ranging from mid adolescence to
4 young adulthood, could affect this. Thus, it is anticipated that the more mature participants would
5 display a higher level of independence in their reaction to the VTE however we found an
6 interconnectedness also described by some of the participants initially diagnosed with VTE in
7 young adulthood. In Hoffman's concept of psychological separation, it is argued that the process
8 of psychological separation from ones' parents is not found until young adulthood (Hoffman,
9 1984). Thus, family adjustment may play an important role not only in adolescents but also
10 young adults adjustment, when adapting to VTE. Thus, our results suggest how the long-term
11 mental well-being of adolescent and young adult VTE patients is affected by, and related to, their
12 families' reaction and adjustment, during a time of developmental transition marked by
13 independence (Sigelman & Rider, 2012).

14 Our findings demonstrate that the perception of being different was profound in life
15 post-VTE. From Meleis' transition theory view, difference is an essential property of illness
16 transition and to not be affected by these differences involves considerable work (Meleis et al.,
17 2000). Accordingly, we found difference related to the social inability to fit in and to being a
18 VTE patient was important for the participants' mental well-being. In line with a study among
19 young diabetes patients (Barnard, Sinclair, Lawton, Young, & Holt, 2012), the participant's
20 ability to fit in with peers was also challenged by alcohol restraint. Grønkjær et al. found alcohol
21 consumption in Denmark to be considered a social necessity and an important factor in being
22 accepted as part of a group, with not drinking considered as not-normal (Grønkjær, Curtis, De
23 Crespigny, & Delmar, 2011). According to Brown and colleagues, peer group affiliation becomes
24 particularly important and influential during adolescence in part solidifying young people's social

1 and personal identity (Brown, Mount, Lamborn, & Steinberg, 1993). Thus, alcohol restraint
2 seems to be an inevitable exposure of ‘being different’ for young Danish VTE patients, and
3 possibly plays a profound role socially and personally. However, this is not an exclusively
4 Danish phenomenon as social drinking is part of the culture in many other western countries
5 (Kuntsche, Rehm, & Gmel, 2004). Our results revealed that the perception of ‘being different’
6 resulted in a feeling of loneliness. Meleis argues that a prominent pattern of response in a healthy
7 illness transition is the need to feel and stay connected (Meleis et al., 2000). Our results suggest
8 that support from family might not constitute such connections, as the participants described
9 feeling alone, despite strong family support. In adolescence and young adulthood a shift in
10 reference group orientation, firstly from parents to peers groups, and later to friends and partners,
11 occurs (Brown et al., 1993). Thus adolescents and young adults increasingly rely on peers for
12 support. Participation in support-groups offers the potential opportunity to feel understood. Our
13 results suggest that the chance to meet and interact with peers who experienced a VTE could
14 play an important role in helping foster healthy mental well-being, as a chance meeting with
15 another young VTE patient was experienced as reassuring and moderated the perception of being
16 alone and different.

17 The results showed heightened body awareness in life after VTE. Similar to Noble
18 and colleagues we also found great concern and negative emotions arose from a heightened state
19 of vigilance towards bodily symptoms indicative of VTE (Noble et al., 2014). This is in
20 accordance with Toombs description of how illness disrupts the lived body and causes the patient
21 to explicitly attend to their body as a body rather than living with it unreflectively (Toombs,
22 1992). Uncertainty and alienation about bodily responses may occur possibly enhanced by the
23 bodily changes and the body image development evident in adolescence and young adulthood
24 (Sigelman & Rider, 2012). The heightened body awareness among the participants was provoked

1 by the initial VTE diagnosis but manifested in the appraisal of future health threat – the fear of
2 recurrence. Thus, the heightened body awareness was not solely a disruption of bodily function
3 related to the initial VTE, it became as Toombs describes it a disruption of the participants’
4 being-in-the-world (Toombs, 1992). Thus, we found that the fear of VTE recurrence had become
5 embodied, and it was central for, the participant’s mental well-being. Moreover we found this
6 fear of recurrence persisted in the long-term which supports previous research suggesting the
7 psychological consequences of VTE have a chronic time course (Bennett et al., 2014; Højen et
8 al., 2015; Noble et al., 2014).

9 The potential role of age was highlighted by the results. Contrary to our findings, in
10 the study by Etchegary et. al. symptom watching and fear of recurrence was observed only in a
11 minority of older VTE patients. (Etchegary et al., 2008). Corbile argues, that because of the
12 absence of previous illness experience, young patients will lack the skills to help them face the
13 uncertainty related to illness, entailing disruption of important life areas and psychological
14 distress (Corbeil, Laizner, Hunter, & Hutchison, 2009). Indeed, the elderly patients in the study
15 by Etchegary et al. perceived the experience of VTE in the context of other illness, which
16 contrasts to the participants in our study and to observations in other studies with a younger
17 sample of patients (Fiandaca et al., 2006; Noble et al., 2014).

18 We found a pronounced insecurity regarding symptom management, amplified by
19 delay in the initial VTE diagnosis. Approximately 20% of VTE patients experienced a delay in
20 diagnosis and there is reason to believe this number is higher in the younger population, because
21 of a lower expectancy of VTE occurrence (Elliott, Goldhaber, & Jensen, 2005). Our findings
22 showed that delay in diagnosis entailed a loss of confidence in health care professionals,
23 supporting previous research (Larsen, Hansen, Olesen, & Vedsted, 2011). It was of importance
24 for the mental well-being of the participants as it entailed uncertainty, and control over the illness

1 became essential. However, in line with Bennett et. al. who observed a lack of personal control
2 over VTE recurrence (Bennett et al., 2014), we found that the perception of control was limited to
3 when symptoms suggestive of VTE recurrence were experienced. In these situations, the
4 participants had to rely on the health care professionals, and they described an overutilization of
5 healthcare services to ensure that VTE recurrence would be recognized.

6 **Limitations**

7 The maximum variation in sampling strengthened the study as it allowed us to gain multiple
8 perspectives and exemplifying complexities. It is important to emphasize that the intention of
9 this variation in sampling was to capture and explore the complexity that lies within the
10 experienced long-term mental well-being and not to assess variation or find causal explanations.
11 This would require a different design and a larger sample size (Guest, Bunce, & Johnson, 2006).
12 Thus, assessing possible variations in experiences among the adolescents and young adults was
13 not the objective of the current study. Denmark is historically a racially and ethnically
14 homogeneous society, which is reflects in our study sample. It could be argued that a variation in
15 ethnicity might have broadened the understanding of adolescents and young adults mental well-
16 being post-VTE. The study was conducted within a Danish context and thereby reflects the
17 culture, norms and values of young Danes. There are cultural differences among adolescents and
18 young adults across the globe, also between western countries, e.g. in regards of alcohol
19 consumption, planning of parenthood and relation to parents (Furlong, 2009). This could affect
20 the transferability of our results. Thus, it would be interesting to explore the psychological
21 impact of VTE in other countries and within different ethnic groups.

22 **Conclusion**

23 The long-term mental well-being of adolescents and young adults diagnosed with VTE is
24 negatively impacted. Mortality is salient in the life of adolescents and young adults following

1 VTE, and manifests particularly in fear of VTE recurrence, which is an important source of
2 psychological distress and persists over time. Hence, VTE is described as something that will
3 always lie in wait. Adolescents and young adults have a perception of being different both among
4 peers and among VTE patients which results in a feeling of isolation. Further, a pronounced
5 insecurity regarding symptom management is evident in life after VTE, amplified by a delayed
6 diagnosis, and concomitant loss of confidence in health care professionals.

7 **Implications for research and practice**

8 This study highlights the clinical importance of including the long-term mental well-being in the
9 overall assessment when developing rehabilitations programs for adolescents and young adults
10 diagnosed with VTE. Perceptions of being different and feeling isolated were evident in life post-
11 VTE and our findings suggest that peer-support could prove beneficial as it may relieve
12 psychological distress by moderating this perception. However further work is required to
13 identify the most suitable form of peer-support. Family, and especially parents' reactions are
14 important for patients mental well-being as they play a major role in the adolescents and young
15 adults illness perceptions and adaption to VTE. Our findings imply that symptom management
16 insecurity may lead to an over-utilization of healthcare services. It was not within the scope of
17 this study to assess and estimate the extent of delay in diagnosis or the subsequent healthcare
18 utilization among young VTE patients, and a larger study exploring this would be relevant.

19 **References**

- 20 Barnard, K., Sinclair, J. M. a., Lawton, J., Young, a. J., & Holt, R. . I. G. (2012). Alcohol-
21 associated risks for young adults with Type 1 diabetes: a narrative review, 434–440.
22 <http://doi.org/10.1111/j.1464-5491.2012.03579.x>
- 23 Bennett, P., Patterson, K., & Noble, S. (2014). Predicting post-traumatic stress and health anxiety

1 following a venous thrombotic embolism. *Journal of Health Psychology*, 1–9.
2 <http://doi.org/10.1177/1359105314540965>

3 Brown, B., Mount, S., Lamborn, S., & Steinberg, L. (1993). Parenting practices and peer groupe
4 affiliation in adolescence. *Child Developpement*, 64, 467–482.

5 Corbeil, A., Laizner, A. M., Hunter, P., & Hutchison, N. (2009). The experience of uncertainty in
6 young adults with cancer. *Cancer Nursing*, 32(5), E17–E27.
7 <http://doi.org/10.1097/NCC.0b013e3181a5690d>

8 DeMaso, D. R., Martini, D. R., Cahen, L. A., Bukstein, O., Walter, H. J., Benson, S., ... Medicus,
9 J. (2009). Practice parameter for the psychiatric assessment and management of physically
10 ill children and adolescents. *Journal of the American Academy of Child and Adolescent*
11 *Psychiatry*, 48(2), 213–33. <http://doi.org/10.1097/CHI.0b013e3181908bf4>

12 Dreyer, P. S., & Pedersen, B. D. (2009). Distanciation in Ricœur’s theory of interpretation:
13 narrations in a study of life experiences of living with chronic illness and home mechanical
14 ventilation. *Nursing Inquiry*, 16(1), 64–73. <http://doi.org/10.1111/j.1440-1800.2009.00433.x>

15 Elliott, C. G., Goldhaber, S. Z., & Jensen, R. L. (2005). Delays in diagnosis of deep vein
16 thrombosis and pulmonary embolism. *Chest*, 128(5), 3372–6.
17 <http://doi.org/10.1378/chest.128.5.3372>

18 Etchegary, H., Wilson, B., Brehaut, J., Lott, A., Langlois, N., & Wells, P. S. (2008). Psychosocial
19 aspects of venous thromboembolic disease: an exploratory study. *Thrombosis Research*,
20 122(4), 491–500. <http://doi.org/10.1016/j.thromres.2007.12.001>

21 Fiandaca, D., Bucciarelli, P., Martinelli, I., Tantardini, F., Clemente, C., & Mannucci, P. M.
22 (2006). Psychological impact of thrombosis in the young. *Internal and Emergency*

- 1 *Medicine*, 1(2), 119–26. <http://doi.org/10.1007/BF02936536>
- 2 Furlong, A. (2009). *Handbook of youth and young adulthood : new perspectives and agendas*.
3 London ;;New York: Routledge Taylor & Francis Group.
- 4 Goldhaber, S. Z., & Bounameaux, H. (2012). Pulmonary embolism and deep vein thrombosis.
5 *Lancet*, 379(9828), 1835–46. [http://doi.org/10.1016/S0140-6736\(11\)61904-1](http://doi.org/10.1016/S0140-6736(11)61904-1)
- 6 Grønkjær, M., Curtis, T., De Crespigny, C., & Delmar, C. (2011). Acceptance and expectance:
7 Cultural norms for alcohol use in Denmark. *International Journal of Qualitative Studies on*
8 *Health and Well-Being*, 6(4), 1–11. <http://doi.org/10.3402/qhw.v6i4.8461>
- 9 Guest, G., Bunce, A., & Johnson, L. (2006). How Many Interviews Are Enough ? An Experiment
10 with Data Saturation and Variability. *Family Health International*, 18(1), 59–82.
11 <http://doi.org/10.1177/1525822X05279903>
- 12 Hammersley, M. (2007). *Ethnography : principles and practice*. London [etc.]: Routledge.
- 13 Hoffman, J. a. (1984). Psychological separation of late adolescents from their parents. *Journal of*
14 *Counseling Psychology*, 31(2), 170–178. <http://doi.org/10.1037/0022-0167.31.2.170>
- 15 Højen, A. A., Gorst-Rasmussen, A., Lip, G. Y. H., Lane, D. A., Rasmussen, L. H., Sørensen, E.
16 E., & Larsen, T. B. (2015). Use of psychotropic drugs following venous thromboembolism
17 in youth. A nationwide cohort study. *Thrombosis Research*, 135(4), 643–7.
18 <http://doi.org/10.1016/j.thromres.2015.01.024>
- 19 Kuntsche, E., Rehm, J., & Gmel, G. (2004). Characteristics of binge drinkers in Europe. *Social*
20 *Science & Medicine*, 59(1), 113–127. <http://doi.org/10.1016/j.socscimed.2003.10.009>
- 21 Larsen, M. B., Hansen, R. P., Olesen, F., & Vedsted, P. (2011). Patients' confidence in their GP

1 before and after being diagnosed with cancer. *British Journal of General Practice*, 61(586),
2 215–222. <http://doi.org/10.3399/bjgp11X572409>

3 Martinez, C., Cohen, a T., Bamber, L., & Rietbrock, S. (2014). Epidemiology of first and
4 recurrent venous thromboembolism: A population-based cohort study in patients without
5 active cancer. *Thrombosis and Haemostasis*, 112(2), 255–63. [http://doi.org/10.1160/TH13-](http://doi.org/10.1160/TH13-09-0793)
6 09-0793

7 Meleis, A. I., Sawyer, L. M., Im, E. O., Hilfinger Messias, D. K., & Schumacher, K. (2000).
8 Experiencing transitions: an emerging middle-range theory. *ANS. Advances in Nursing*
9 *Science*, 23(1), 12–28. <http://doi.org/10.1046/j.1440-1800.1999.00015.x>

10 Moore, T., Norman, P., Harris, P. R., & Makris, M. (2006). Cognitive appraisals and
11 psychological distress following venous thromboembolic disease: an application of the
12 theory of cognitive adaptation. *Social Science & Medicine* (1982), 63(9), 2395–406.
13 <http://doi.org/10.1016/j.socscimed.2006.06.014>

14 Noble, S., Lewis, R., Whithers, J., Lewis, S., & Bennett, P. (2014). Long-term psychological
15 consequences of symptomatic pulmonary embolism: a qualitative study. *BMJ Open*, 4(4),
16 e004561. <http://doi.org/10.1136/bmjopen-2013-004561>

17 O'Reilly, M., & Parker, N. (2012). “Unsatisfactory Saturation”: a critical exploration of the
18 notion of saturated sample sizes in qualitative research. *Qualitative Research*, 13, 190–197.
19 <http://doi.org/10.1177/1468794112446106>

20 Regmi, K., Naidoo, J., & Pilkington, P. (2010). Understanding the Processes of Translation and
21 Transliteration in Qualitative Research. *International Journal of Qualitative Methods*, 9, 16–
22 26.

- 1 Ricœur, P. (1973). The Hermeneutical Function of Distanciation. *Philosophy Today*, 2(17:2
2 (1973:Summer)), 129–141.
- 3 Ricœur, P. (1981). *Hermeneutics and the human sciences: Essays on language, action, and*
4 *interpretation*. Cambridge [England]: Cambridge University Press.
- 5 Sigelman, C. K., & Rider, E. A. (2012). *Human development across the life span*. BOOK,
6 [Belmont, Calif.?]: Wadsworth Cengage Learning.
- 7 Skaali, T., Fosså, S. D., Bremnes, R., Dahl, O., Haaland, C. F., Hauge, E. R., ... Dahl, A. a.
8 (2009). Fear of recurrence in long-term testicular cancer survivors. *Psycho-Oncology*, 18(6),
9 580–8. <http://doi.org/10.1002/pon.1437>
- 10 Spradley, J. (1980). Making descriptive observations. In *Participant observation* (pp. 73–85).
11 New York: Holt Rinehart and Winston.
- 12 Thompson, R., & Gustafson, K. E. (1999). *Adaptation to chronic childhood illness. Adaptation to*
13 *chronic childhood illness*. Washington D.C.: American Psychological Association.
- 14 Toombs, S. K. (1992). *The meaning of illness: A phenomenological account of the different*
15 *perspectives of physician and patient*. Dordrecht: Kluwer Academic Publishers.
- 16 Zoffmann, V., Vistisen, D., & Due-Christensen, M. (2014). A cross-sectional study of glycaemic
17 control, complications and psychosocial functioning among 18- to 35-year-old adults with
18 type 1 diabetes. *Diabetic Medicine: A Journal of the British Diabetic Association*, 31(4),
19 493–9. <http://doi.org/10.1111/dme.12363>

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21

1 **Table 1.** Participant characteristics

Characteristic			2
Age at study inclusion, years			3
Mean (SD)	24.8 (4.9)		4
Range	17-33		5
Age at first VTE			6
Mean (SD)	20.9 (5.2)		7
Range	14-30		8
Female, n (%)	9 (75)		9
Recurrent VTE, n (%)	7 (58)		10
Living circumstances (%)			11
With parents	3 (25)		12
With partner	6 (50)		13
Alone	3 (25)		14
Children, n (%)	3 (25)		15
VTE type			16
DVT	3 (25)		17
PE	1 (8)		18
DVT+PE	8 (67)		19
Life-long anticoagulant treatment	6 (50)		20
			21
			22
			23
			24

25
26

Sh it was a close call**

Getting a blood clot is a serious thing, but at the time I had the blood clots, it actually didn't feel like it, because it was too unreal. I didn't feel as bad as I actually was. What scared me the most was actually to see my parents' reaction. When they talk about it, they almost cry – I think that is the really scary part, that it can make my father cry; then I know it was critical back then, and then you kind of realize: "sh** it was a close call". It is not until now, afterwards, I am beginning to realize that it was a blood clot and not just something flu-like I had. It actually was truly critical, and it can stay with you. You become aware of how nothing lasts forever, and it is kind of a wake-up call. - Stop, think about what you are doing and who you are.

I am not like the others anymore

After the blood clot, I suddenly felt different. I wasn't like the others anymore. For instance, I can't drink alcohol because of the medicine I take. And that makes me feel excluded from certain things, and stops me from really being part of the group. Then you don't really feel normal. I also have to wear a compression stocking; you feel a little weird when you have to wear those darn compression stockings. It's embarrassing, especially during the summer and at PE. I can see people think: "That is quite strange". You know, people don't really understand it, and do not get how it is, and what it is. Of course, they listen when I speak, but I don't really feel understood. A blood clot is something an old lady has, and it makes you reflect. - You are bit of a loner. Then it is really nice to meet somebody who has experienced some of the same, because we understand each other and relate to each other and share our experiences.

It is always looming in the background

The blood clot really fills up my brain, it is hard to explain why, but in a way it is always there, lurking. I have to take medicine every day, and my leg swells a lot, so it's in some way always present. Every day it is a part of my life. There are also a lot of thoughts; is it going to affect me again? Is it something I will pass on to my children? And what will happen if I get pregnant? I have often thought: "I am not ill", and "I am like everybody else" But you're not, because you will always have to bear in mind that it can happen again. Sometimes, I feel like it will definitely happen again. I know I have been told it shouldn't happen when I take my medicine, but I still feel like – One thing is what they say; another thing is what will happen next time. I have accepted that my body has a flaw, that I am the weak link now. I have become more aware of what happens in my body, what it complains about, and I notice more things now than I did before. When I lie down in bed, I get this sensation and I ruminate. In that way, it makes itself present in a stronger way than you think it would.

I could actually have died of this!

I saw my GP and the on-call GP several times before they found out it was a blood clot. And you can feel a bit annoyed they didn't do more. I could actually have died of this. I lost a lot of confidence in the doctors. It helped a bit when shortly after having the clot my GP explained to me how hard it actually can be to detect it. But when you have been through this, you know you have to trust yourself and not always trust doctors blindly. Sometimes you have to put your foot down and tell them, "Well this is how I feel" because I want people to take me serious when it is something related to the blood clot. Sometimes I can hear myself make matters worse to be sure they will check me out. It is tough, because it is all up to the doctor; does he send me home or send me on? I'd rather be admitted and checked out when I feel something, because there may be something there and there may not. There must have been 5-6 times where they found nothing.

1 **Table 2.** The stories: My life after VTE

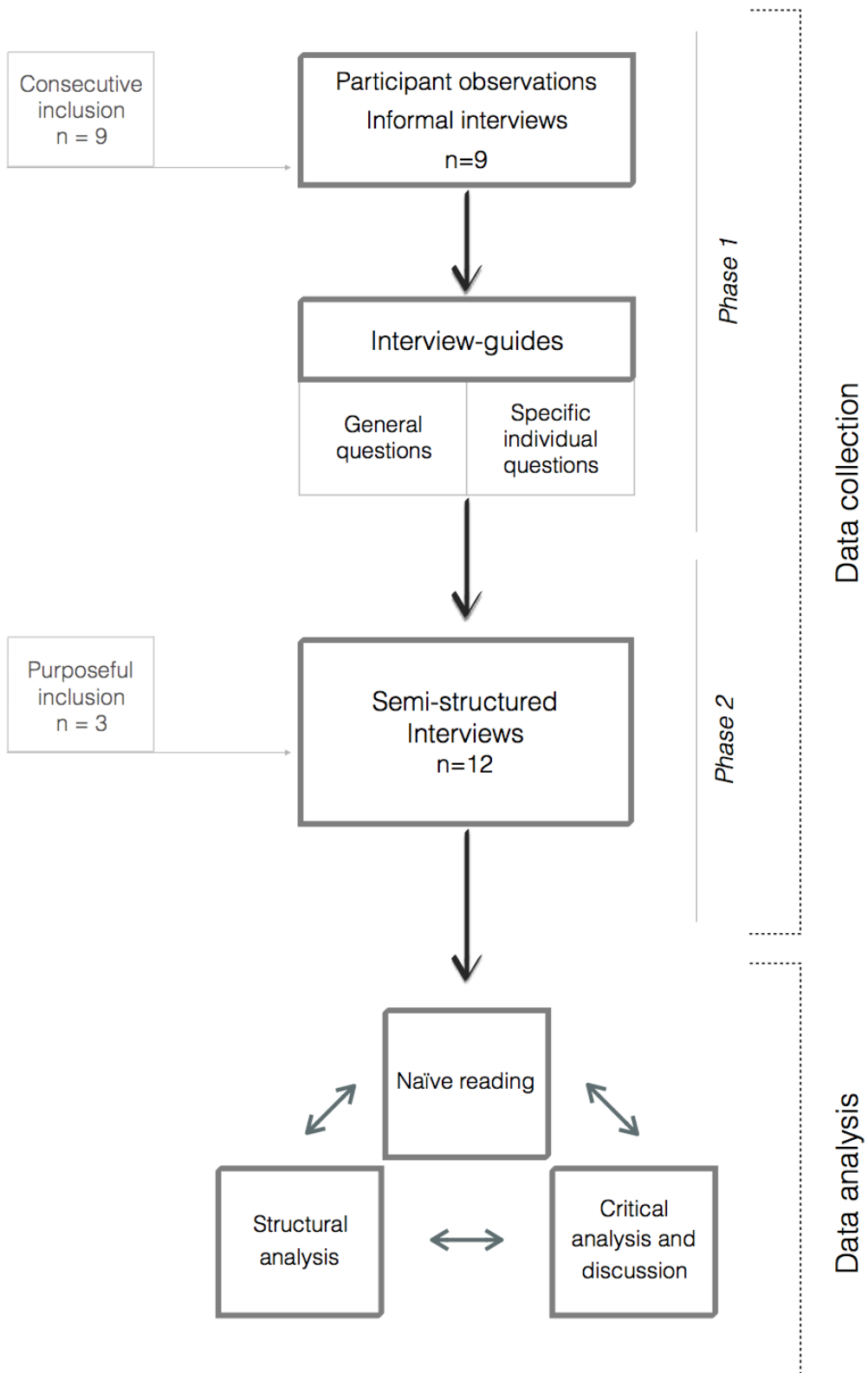
2 DVT = deep venous thrombosis; PE = pulmonary embolism; SD = standard deviation; VTE = venous
3 thromboembolism

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- 1 **Figure legends**
- 2 **Figure 1. Study design**



1

2 **Supplementary table 1.** Translation of Stories

Danish	English
<p><i>Shit hvor var det bare tæt på</i></p> <p>At få en blodprop er en alvorlig ting, men dengang jeg fik blodpropperne føltes det faktisk ikke sådan, for det var alt for uvirkeligt. Jeg følte ikke, jeg havde det så skidt, som jeg egentlig havde det. Det, der skræmte mig mest, var egentlig at se mine forældres reaktion. Når de fortæller om det, så er det lige før de giver sig til at tude - det synes jeg virkelig er skræmmende, at det ligefrem kan få min far til at græde, så ved jeg det var slemt dengang. Så får man det sådan lidt: ”shit hvor var det bare tæt på.” Det er først her bagefter, det er ved at gå op for mig, at det faktisk var blodpropper, og ikke bare influenza jeg havde. Det var jo faktisk rigtig alvorligt, og det kan godt sidde i én. Man bliver bevidst om, at der ikke er noget der varer evigt, og det er sådan lidt et opvågningskald. Stop op og tænk over hvad du gør, og hvem du er.</p>	<p><i>Sh** it was a close call</i></p> <p>Getting a blood clot is a serious thing, but at the time I had the blood clots, it actually didn't feel like it, because it was too unreal. I didn't feel as bad as I actually was. What scared me the most was actually to see my parents' reaction. When they talk about it, they almost cry – I think that is the really scary part, that it can make my father cry; then I know it was critical back then, and then you kind of realize: “sh** it was a close call”. It is not until now, afterwards, I am beginning to realize that it was a blood clot and not just something flu-like I had. It actually was truly critical, and it can stay with you. You become aware of how nothing lasts forever, and it is kind of a wake-up call. - Stop, think about what you are doing and who you are.</p>
<p><i>Jeg er ikke som de andre mere</i></p> <p>Efter blodproppen følte jeg mig pludselig anderledes. Jeg var ikke længere ligesom alle de andre. Jeg må fx ikke rigtig drikke alkohol på grund af den medicin jeg får. Det gøre, at jeg føler mig udelukket fra nogen ting, og jeg</p>	<p><i>I am not like the others anymore</i></p> <p>After the blood clot, I suddenly felt different. I wasn't like the others anymore. For instance, I can't drink alcohol because of the medicine I take. And that makes me feel excluded from certain things, and stops me from really being part of the group. Then you don't really feel</p>

<p>er derfor heller ikke er med i fællesskabet. Så føler man sig ikke særlig normal. Jeg skal også have støttestrømpe på. Man er lidt speciel, når man skal have den skide støttestrømpe på. Det er flovt, især til idræt og om sommeren. Jeg kan se, at folk de tænker: det er godt nok mærkeligt. Folk de forstår det jo ikke rigtigt, de kan ikke rigtig sætte sig ind i, hvordan det er, og hvad det er for noget. Ja, de lytter når jeg fortæller, men jeg føler mig ikke rigtig forstået. En blodprop er noget gamle mennesker får, og det får en til at tænke, at man er lidt en ener, der er anderledes end de andre. Så det er virkelig rart at møde én, som har prøvet det, for vi forstår hinanden og udveksler erfaringer og relaterer til hinanden.</p>	<p>normal. I also have to wear a compression stocking; you feel a little weird when you have to wear those darn compression stockings. It's embarrassing, especially during the summer and at PE. I can see people think: "That is quite strange". You know, people don't really understand it, and do not get how it is, and what it is. Of course, they listen when I speak, but I don't really feel understood. A blood clot is something an old lady has, and it makes you reflect. - You are bit of a loner. Then it is really nice to meet somebody who has experienced some of the same, because we understand each other and relate to each other and share our experiences.</p>
<p><i>Det ligger hele tiden og lur</i></p> <p>Blodproppen fylder virkelig meget i min hjerne, det er svært at forklare hvorfor, men det ligger bare hele tiden og lur på en eller anden måde. Jeg skal tage piller hver dag, og mit ben det hæver meget op, så blodproppen er jo noget jeg mærker til. Hver dag er det en del af mit liv. Der er også mange sådan tanker; kommer det til at påvirke mig igen; er det noget, jeg fører videre til mine børn; og hvad sker der, hvis jeg bliver gravid? Jeg har tit tænkt: "nej jeg er ikke syg", og "jeg er ligesom de andre." Men det er man ikke, for man skal altid gå og tænke på, at det kan ske igen. Nogen gange har jeg</p>	<p><i>It is always looming in the background</i></p> <p>The blood clot really fills up my brain, it is hard to explain why, but in a way it is always there, lurking. I have to take medicine every day, and my leg swells a lot, so it's in some way always present. Every day it is a part of my life. There are also a lot of thoughts; is it going to affect me again? Is it something I will pass on to my children? And what will happen if I get pregnant? I have often thought: "I am not ill", and "I am like everybody else" But you're not, because you will always have to bear in mind that it can happen again. Sometimes, I feel like it will definitely happen</p>

<p>det, som om det vil ske igen. Jeg ved godt, at jeg har fået at vide, at det ikke burde kunne ske når jeg er i behandling, men jeg har det stadigvæk sådan - En ting er hvad de siger, noget andet er hvad der sker næste gang? Jeg har accepteret at min krop har fejl, at jeg lidt er det svage led nu. Jeg er blevet mere opmærksom på, hvad der foregår i kroppen, hvad den brokker sig over, og jeg kan mærke flere ting nu, end jeg kunne førhen. Jeg kan godt ligge og sådan mærke efter, få den her følelse og spekulere. På den måde fylder det mere end man umiddelbart tænker over.</p>	<p>again. I know I have been told it shouldn't happen when I take my medicine, but I still feel like – One thing is what they say; another thing is what will happen next time. I have accepted that my body has a flaw, that I am the weak link now. I have become more aware of what happens in my body, what it complains about, and I notice more things now than I did before. When I lie down in bed, I get this sensation and I ruminate. In that way, it makes itself present in a stronger way than you think it would.</p>
<p><i>Jeg kunne faktisk have været død af det her!</i></p> <p>Jeg var ved lægen og lægevagten flere gange, inden de fandt ud af, at det var en blodprop, og man kan godt blive irriteret over, at de ikke gjorde lidt mere. Jeg kunne faktisk have været død af det her. Det gjorde, at jeg mistede tilliden til lægerne. Det hjalp lidt at min læge kort tid efter blodproppen forklarede mig, hvor svært det reelt kan være at opdage. Men når man har været igennem det, så ved man, at man skal stole på sig selv, og at man ikke altid skal stole blindt på lægerne. Man er nødt til nogen gange at banke i bordet og sige: jamen det er sådan jeg føler. For jeg vil have at folk tager mig seriøst, hvis det er noget omkring blodproppen. Jeg kan nogle gange høre mig selv gøre tingene værre for at være sikker på, at</p>	<p><i>I could actually have died of this!</i></p> <p>I saw my GP and the on-call GP several times before they found out it was a blood clot. And you can feel a bit annoyed they didn't do more. I could actually have died of this. I lost a lot of confidence in the doctors. It helped a bit when shortly after having the clot my GP explained to me how hard it actually can be to detect it. But when you have been through this, you know you have to trust yourself and not always trust doctors blindly. Sometimes you have to put your foot down and tell them, "Well this is how I feel" because I want people to take me serious when it is something related to the blood clot. Sometimes I can hear myself make matters worse to be sure they will check me out. It is tough, because it is all up to the</p>

jeg bliver kikket på. Det er svært, fordi det er lægen som står med det hele; og sender han mig hjem eller sender han mig videre? Jeg vil hellere, at han indlægger mig, og jeg bliver tjekket når jeg mærker noget, for der kan jo ligeså godt være noget, som der ikke kan være noget. Jeg har nok været inde 5, 6 gange, hvor der ikke har været noget.

doctor; does he send me home or send me on? I'd rather be admitted and checked out when I feel something, because there may be something there and there may not. There must have been 5-6 times where they found nothing.

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1 **Supplementary table 2.** Translation of Quotations

2

Danish	English
Bliver mere opmærksom på, hvor lidt der skal til.	Become aware of how little it takes.
Der er ikke noget, der varer evigt.	That nothing lasts forever.
Min mor hun har fortalt, at hun synes, at jeg var sådan lidt blålig i hovedet, og hun kunne se jeg virkelig manglede ilt i kroppen, det havde skræmt dem [...] Jeg kan ikke selv huske det var så slemt, men altså efterfølgende, når man sådan går og tænker over det, jamen det gør mig da nok lidt bange, fordi det var nok mere tæt på, end jeg lige troede.	My mother told me, my face turned blue, and they could see how my body desperately needed oxygen, and this really frightened them. I don't remember it being that bad, but now afterwards, when you think about it, well, it scares me, because it was probably a closer call than I had thought.
Det var rigtig rigtig hårdt, jeg er ikke vant til at se min far græde. Han har altid været sådan en hård nyser synes jeg [...] han græder aldrig, men der grad han godt nok, det var meget voldsomt for mig at se.	It was really, really tough; I am not used to seeing my father cry. He has always been one tough cookie. He never cries. It was very scary to experience.
Jeg var pisse bange og havde mareridt, drømte jeg brændte op, altså der begyndte alt det følelsesmæssige ligesom at komme ind i det, at jeg faktisk kunne have været død.	I was scared sh**less and had nightmares, dreamt I burned alive. Well, at that point all the emotional stuff began to emerge, that I actually could have died.
En kamp lige siden.	On-going fight.
Jeg følte mig pludselig anderledes end de andre, det synes jeg nok var det sværeste, at jeg sådan lige pludseligt, så var jeg ikke ligesom alle de andre mere.	Suddenly I felt different than the others, I think that was hardest, that I suddenly wasn't like the others anymore.
Man føler sig jo bare lidt udenfor, altså når du ikke kan deltage i; når du ikke kan drikke dig fuld og være glad sammen med de andre, så	You just feel a little left out when you can't participate; when you can't get drunk and be happy in the company of the others, then the

<p>bliver festen bare lidt anderledes for dit vedkommende, så er du med men ikke på samme måde.</p>	<p>party becomes different for you, you're a part of it, but not in the same way.</p>
<p>De fleste siger det der med, at det var ikke lige det man havde forestillet sig en pige på din alder skulle igennem, og det er også det jeg selv tænker. Nu har jeg lige fået en af pjecerne igen, hvor at samtlige billeder, der er i den, er nogen der går med kryk eller rollator[...]det får en til at tænke, hold da op man er lidt en ener.</p>	<p>Most people say that it's really not what you would expect a girl of your age to go through, and that's what I think as well. I just got one of the pamphlets again, and all the pictures in it are of somebody walking with a crutch or a walker [...] it makes you think, you are a bit like a loner.</p>
<p>Jeg føler mig egentlig lidt alene, og jeg ved det lyder bare så dumt på en eller anden måde, for jeg har en sød kæreste og familie og sådan noget, men altså de, det er bare så svært at forklare, de lytter og sådan noget, men jeg føler mig ikke rigtig forstået.</p>	<p>I actually feel alone, I know it sounds stupid in a way, I have a nice boyfriend and family, it is just so hard to explain; it's just, they listen and stuff, but I don't really feel understood.</p>
<p>Det er betryggende på en eller anden måde, at man ikke kun alene har oplevet det her, at der også er en anden, som har prøvet det og kan relater til det.</p>	<p>It is reassuring in some way that you are not alone in having experienced this, that somebody else has experienced it and can relate to it.</p>
<p>Det kommer til at hænge ved mig resten af livet. Som sådan en lille sky, der svæver i din bevidsthed om, at det er sådan det er.</p>	<p>This will stick with me for the rest of my life, like a little cloud that floats in your mind, that is how it is.</p>
<p><i>Jeg er blevet mere opmærksom end normalt, jeg kan mærke flere ting nu, end jeg kunne førhen. Man tager for givet som det kører i kroppen, det tænker man jo ikke over, det kan jeg så mærke nu, jeg kan mærke det hele I kroppen nu [...]jeg må være mere opmærksom</i></p>	<p>I have become more alert than I used to. I can feel more things now, than I could previously. You take it for granted, how your body works. You don't think about it. Now I do. I feel everything in my body now. I have to be more alert of what my body does, what it complains</p>

<i>på, hvad kroppen gør og hvad den brokker sig over, så jeg næste gang er lidt mere opmærksom.</i>	about, so I can be more observant next time.
Hvis jeg har ondt og ikke kan forstå, hvorfor jeg har ondt, så kan det godt få mig til sådan virkelig at græde. Og jeg vil faktisk sige at smerterne under forløbet, det har ikke engang været det værste, det har faktisk været det efterfølgende, den psykiske smerte.	If I am in pain and can't understand what is wrong, it really makes me cry, and actually I would say that the physical pain during this has not been the worst, it is the mental pain that came after that was the worst.
Det kunne jeg godt mærke, at det sparkede altså lige en tilbage i det der, så jeg havde det rigtig rigtig hårdt med det	I could feel how it kicked me right back into it; I found it to be really, really tough.
Hvis du ikke ved hvor det kommer fra, så kan man jo ikke vide, om det kommer igen	If you don't know where it came from you cannot know whether it will come back again.
Selvom jeg jo fik at vide, at så længe jeg tager mit medicin, så kan det ikke ske igen, men det er bare ikke nok. Det, ja det er den der angst, tror jeg, for at det sker igen.	Even though I was told, that it can't happen again as long as I take my medicine, it's still just not enough. It is the anxiety I think, the fear that this could happen again.
Det var så voldsomt, at tre læger og min egen mere end en gang overhørte mine signaler. Jeg følte ikke, jeg kunne stole på nogen af lægerne og det gør jeg stadigvæk ikke rigtigt.	It was so disturbing how three doctors, as well as my GP more than once, could disregard my signals, I didn't feel I could trust any doctors, and I still don't.
Lige pludselig er det bare blevet super vigtigt for mig, at der er styr på det, og jeg kan bedst have styr på det, hvis jeg kan styre det selv. Den der kontrol i at vide, at jeg ved, hvad det handler om.	Suddenly it has become super important to me, that everything is under control, and I am best in control if I control it myself. The control in knowing, that I know what it is all about.
At starte på en frisk	To make a fresh start.
Indimellem, så kan jeg høre mig selv, jeg gør tingene værre bare for at være sikker på, de gider kigge på mig, altså at de bare vil høre	Sometimes I can hear myself make matters worse, just to make sure they will take a look at me, and to make sure they will listen to me and

efter, hvad det egentlig er, jeg sidder og siger, altså, og at de kan se selv. Så vil jeg hellere, at jeg bliver sendt hjem og får at vide; at ved du hvad, det virker ikke til at være noget.	to what I am telling them. I'd rather they have a look at me and then be sent home with the message that everything seems fine.
Hellere de finder ud af der ikke er noget end det viser sig der er noget, så hellere ryge ind 40 gange på et år.	I rather they find out nothing is wrong, than something shows up. I would rather be admitted 40 times in one year.

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