

## PEER REVIEW HISTORY

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### ARTICLE DETAILS

<b>TITLE (PROVISIONAL)</b>	Long-term psychosocial impact of venous thromboembolism: a qualitative study in the community
<b>AUTHORS</b>	Hunter, Rachael; Noble, Simon; Lewis, Sarah; Bennett, Paul

### VERSION 1 – REVIEW

<b>REVIEWER</b>	Anette Arbjerg Højen Aalborg University Hospital, Denmark
<b>REVIEW RETURNED</b>	10-Jul-2018

<b>GENERAL COMMENTS</b>	<p>The paper covers an important aspect of VTE management. The manuscript describes a study on the long-term psychosocial impact of venous thromboembolism. The interview study has a longitudinal design and data is analysed using inductive thematic analysis. Findings includes four themes and indicate that the psychosocial impact of VTE is psychologically challenging. I find the study highly relevant, and the findings are indeed interesting and important. I have the following comments:</p> <ol style="list-style-type: none"> <li>1. It would improve the manuscript if the authors would include some of the other relevant literature on the psychosocial effects of life threatening/chronic illness for the individual and quality of life, to argue the case for conducting the study.</li> <li>2. How the analysis was carried out is very well described, but a greater specificity in the augment for the chosen method would be relevant. Also, the authors did not describe how they would ensure the rigor and trustworthiness of the data as required in qualitative studies.</li> <li>3. Do the authors have information on the reason why the patient opted out of the study?</li> <li>4. The longitudinal design reflects nicely in the discussion. However, it could be clearer how the longitudinal nature of this study shows in the results. How do the findings differ/relate/elaborate on the findings from the first interviews? To argue for the benefit/reason of the longitudinal design, it would be relevant to more actively show this throughout the result section and then discuss these findings in the discussion section. Perhaps restructuring the result and discussion section, as some of the discussion could be argued to be findings in this longitudinal study.</li> <li>5. Did all patients report their life to have been changed, to have negative emotions and experience uncertainty etc.? Or did some patients feel their life was not changed? If so it would be relevant to include this to show the variety in experiences, still focused on the</li> </ol>
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	<p>authors very relevant findings.</p> <p>6. Did the “relevant information” in table 1 influence the results? Also, the treating part could be influential: do you have information on was weather the treatment initiated and controlled by GP’s, a hospital-based clinic or a combination?</p> <p>7. It would improve this manuscript to include more detailed discussion of results using the available literature to explain the significance of findings and why these findings are important. E.g. litterateur on psychosocial impact of illness, uncertainty, reaction to VTE in different age groups, symptom management, anticoagulant management, meaning of illness etc. A restructuring of the result and discussion sections would allow for a more detailed discussion of results.</p> <p>8. There is no discussion on patient inclusion (how did the authors determine that the sample was adequate), the patient loss to follow-up, or data saturation.</p> <p>9. There is a star indicating a reference to a figure legend for the patient who opted out, but no figure legend is presented.</p>
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<b>REVIEWER</b>	Stefano Barco Center for Thrombosis and Hemostasis, University Medical Center of the Johannes Gutenberg University, Mainz, Germany
<b>REVIEW RETURNED</b>	15-Aug-2018

<b>GENERAL COMMENTS</b>	<p>The authors performed a longitudinal qualitative interview study using inductive thematic analysis. A total of 11 patients with a first episode of VTE diagnosed 6 months before have been interviewed. This study contributes to highlight the psychosocial impact of VTE on patients’ lives, but, at the same time, the presence of individual differences in the perception of the disease, which are likely influenced also by personal, anamnestic, therapeutic, social, and environmental factors. The authors should be congratulated for their effort and work.</p> <p>* Could they discuss why there was no formal assessment of validated QoL questionnaires?</p> <p>* It appears that VTE may represent a specific ‘illness as metaphor’ with own patterns and characteristics. The authors could discuss more in detail the patients’ use of symbolic language and metaphors for referring to VTE, and perhaps compare it to their personal experience.</p> <p>* Bleeding events and risk are hardly mentioned. Could the authors extract information on this relevant complication?</p> <p>* Can the authors speculate about historical changes in the psychosocial impact of VTE? Do they think that the improved knowledge of the disease and general awareness modified the psychosocial impact of VTE e.g. as compared to 2-3 decades ago when ‘the patient got phlebitis’?</p>
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<b>REVIEWER</b>	Susann Strang The Sahlgrenska Academy, Institute of Health and Care Sciences, Gothenburg, Sweden
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<b>REVIEW RETURNED</b>	30-Oct-2018
<b>GENERAL COMMENTS</b>	<p>Thank you for the opportunity to review this paper. This is a well-written and important study, although a minor number of participants. You had an exemplary short and meaningful introduction, and method section and a relevant discussion. The only thing I was hesitant about was the number of quotes in the result-section (more than 30). This gives me a feeling that the thematic interpretation is unfinished and unprocessed. Would you please rework the result text and incorporate some (min10) of your quotes in the body text so that your interpretation of the interview comes forth in a more stringent way.</p> <p>Furthermore, the result part would be strengthened if it would be a bit shorter.</p> <p>I wish you all the best and I appreciate your important work!</p>

### VERSION 1 – AUTHOR RESPONSE

Reviewer: 1

Reviewer Name: Anette Arbjerg Højen

Institution and Country: Aalborg University Hospital, Denmark Please state any competing interests or state 'None declared': None declared

The paper covers an important aspect of VTE management. The manuscript describes a study on the long-term psychosocial impact of venous thromboembolism. The interview study has a longitudinal design and data is analysed using inductive thematic analysis. Findings includes four themes and indicate that the psychosocial impact of VTE is psychologically challenging. I find the study highly relevant, and the findings are indeed interesting and important.

I have the following comments:

1. It would improve the manuscript if the authors would include some of the other relevant literature on the psychosocial effects of life threatening/chronic illness for the individual and quality of life, to argue the case for conducting the study. Page 4, line 13-15. Due to restrictions from the word-count, exploration of this is limited.
2. How the analysis was carried out is very well described, but a greater specificity in the augment for the chosen method would be relevant. Also, the authors did not describe how they would ensure the rigor and trustworthiness of the data as required in qualitative studies. See page 5, line 17-18 and page 6, line 11-13.
3. Do the authors have information on the reason why the patient opted out of the study? Please see page 5, line 2-3. No information was forthcoming regarding the participant's decision not to participate at time 2.
4. The longitudinal design reflects nicely in the discussion. However, it could be clearer how the longitudinal nature of this study shows in the results. How do the findings differ/relate/elaborate on the findings from the first interviews? To argue for the benefit/reason of the longitudinal design, it would be relevant to more actively show this throughout the result section and then discuss these findings in the discussion section. Perhaps restructuring the result and discussion section, as some of the discussion could be argued to be findings in this longitudinal study. We had considered an extended consideration of the longitudinal nature of the study in the results section but decided that in order to avoid confusion about which results were being discussed the current structure was clearer for the

reader. Furthermore, it enabled the consideration of participants' experiences during this interesting post-VTE period; i.e. when they had passed through initial treatment into longer term management. The Time Two findings are then considered more widely in the context of the time one findings in the discussion, within the word count afforded.

5. Did all patients report their life to have been changed, to have negative emotions and experience uncertainty etc.? Or did some patients feel their life was not changed? If so it would be relevant to include this to show the variety in experiences, still focused on the authors very relevant findings. Page 6, line 1. All participants reported their life changed to some degree.

6. Did the "relevant information" in table 1 influence the results? Also, the treating part could be influential: do you have information on was weather the treatment initiated and controlled by GP's, a hospital-based clinic or a combination? The 'relevant information' has been presented for the reader to consider alongside the results, although interpretations regarding this are limited the authors felt this was in keeping with the thematic analysis (as opposed to a more interpretative analytic approach).

7. It would improve this manuscript to include more detailed discussion of results using the available literature to explain the significance of findings and why these findings are important. E.g. literature on psychosocial impact of illness, uncertainty, reaction to VTE in different age groups, symptom management, anticoagulant management, meaning of illness etc. A restructuring of the result and discussion sections would allow for a more detailed discussion of results. We acknowledge that due to the limitations of the word count and the presentation of qualitative results, extended consideration of the wider literature is limited. Efforts have been made to contextualise the findings (page 17, line 23-24; page 18, line 3-4; page 18, line 11-17. Consideration of the implications for different age groups are discussed (page 17, line 20 to page 18, line 3). In relation to the structure of the discussion, see comments for point 4.

8. There is no discussion on patient inclusion (how did the authors determine that the sample was adequate), the patient loss to follow-up, or data saturation. Amended; see Page 6, line 12-13.

9. There is a star indicating a reference to a figure legend for the patient who opted out, but no figure legend is presented. Amended, see page 20, line 2-3.

Reviewer: 2

Reviewer Name: Stefano Barco

Institution and Country: Center for Thrombosis and Hemostasis, University Medical Center of the Johannes Gutenberg University, Mainz, Germany Please state any competing interests or state 'None declared': None declared

The authors performed a longitudinal qualitative interview study using inductive thematic analysis. A total of 11 patients with a first episode of VTE diagnosed 6 months before have been interviewed. This study contributes to highlight the psychosocial impact of VTE on patients' lives, but, at the same time, the presence of individual differences in the perception of the disease, which are likely influenced also by personal, anamnestic, therapeutic, social, and environmental factors. The authors should be congratulated for their effort and work.

\* Could they discuss why there was no formal assessment of validated QoL questionnaires? As this was a qualitative exploratory study, formal assessment was not deemed relevant during design. Furthermore, this was an interview-based study. Furthermore, this study was part of a wider project in which quantitative and formal assessment were included.

\* It appears that VTE may represent a specific ‘illness as metaphor’ with own patterns and characteristics. The authors could discuss more in detail the patients’ use of symbolic language and metaphors for referring to VTE, and perhaps compare it to their personal experience. See page 17, line 17-19. The word count does not allow for depth of exploration, but efforts have been made to highlight the use of metaphor by participants.

\* Bleeding events and risk are hardly mentioned. Could the authors extract information on this relevant complication? Efforts have been made to highlight where anxieties are associated with bleeding risks. For example, page 11, 17-23. Page 12, line 22; page 17, line 13.

\* Can the authors speculate about historical changes in the psychosocial impact of VTE? Do they think that the improved knowledge of the disease and general awareness modified the psychosocial impact of VTE e.g. as compared to 2-3 decades ago when ‘the patient got phlebitis’? Unfortunately, the word count does not allow for such extended socio-cultural exploration without detracting from the key findings and their full description.

Reviewer: 3

Reviewer Name: Susann Strang

Institution and Country: The Sahlgrenska Academy, Institute of Health and Care Sciences, Gothenburg, Sweden Please state any competing interests or state ‘None declared’: None declared

Thank you for the opportunity to review this paper. This is a well-written and important study, although a minor number of participants. You had an exemplary short and meaningful introduction, and method section and a relevant discussion.

The only thing I was hesitant about was the number of quotes in the result-section (more than 30). This gives me a feeling that the thematic interpretation is unfinished and unprocessed. Would you please rework the result text and incorporate some (min10) of your quotes in the body text so that your interpretation of the interview comes forth in a more stringent way. Five quotes have been deleted to ensure that the rigour of the analysis is more apparent (e.g. page 7, quote 2; page 8, quote 1; page 10 quote 3; page 12, quote 4; page 16, quote 1).

Furthermore, the result part would be strengthened if it would be a bit shorter.

I wish you all the best and I appreciate your important work!

#### VERSION 2 – REVIEW

<b>REVIEWER</b>	Susann Strang The Sahlgrenska Academy at UNIVERSITY OF GOTHENBURG Institute of Health and Care Sciences Box 457 , 405 30 Göteborg, Sweden
<b>REVIEW RETURNED</b>	13-Dec-2018
<b>GENERAL COMMENTS</b>	Congratulations to a very good article!