

# **BY CREATING A LIFE, I AM PUTTING MINE IN JEOPARDY: EXPERIENCES AND FEELINGS OF WOMEN SUFFERING FROM THE LEIDEN MUTATION, AND THEIR PARTNERS, WITH BECOMING PARENTS**

**Anna Ziklova**

*Department of Psychology, Faculty of Arts, Masaryk University (Czech Republic)*

## **Abstract**

*Background:* The Leiden mutation, one of the most frequently diagnosed thrombophilias, is supposedly connected to increased risk of thrombosis during pregnancy and other pregnancy-related complications, including recurrent pregnancy loss, preeclampsia or excessive postpartum haemorrhage. As of to date, scholarly sources have not yet proven a direct causal relation between the Leiden mutation and pre-, peri- or postnatal complications. The study aimed to explore how women diagnosed with the Leiden mutation, together with their partners, experienced pregnancy-related complications in different phases of gestation, what emotions they felt and which coping strategies they utilised.

*Method:* A pilot qualitative exploratory study was conducted using semi-structured interviews. The data were analysed using Interpretative Phenomenological Analysis (IPA).

*Findings:* In the research sample (N=4, F=3, M=1, m = 36), which included one heterosexual couple, a variability in experiencing and feelings based on the course of pregnancy, frequency and severity of pregnancy complications was identified, including: lack of information about potential risks, trivialization of the diagnosis, fear of losing the baby, distrust in the prophylactic treatment or fear of harming the baby with the treatment. Social support and relationship satisfaction were recognised as key protective factors for the mental health of female participants, whereas emotional instability and maladaptive coping strategies, particularly depressive tendencies, emerged as significant psychological risks. For the male participant, a rational and pragmatic way of thinking functioned as a protective factor.

*Conclusion/Impact:* The results of this exploratory study provided a unique insight into the underexplored phenomenon of experiencing pregnancy complications while being diagnosed with the Leiden mutation. The findings may be beneficial for future psychological research and clinical practice not only in the Czech Republic.

*Keywords:* *Leiden mutation, pregnancy complications, feelings, experiences, protective and risk factors.*

---

## **1. Introduction**

The Factor V Leiden (FVL) mutation is one of the most commonly inherited thrombophilias, particularly in its heterozygous form, and is associated with a five- to eight-fold increased risk of venous thromboembolism (VTE) during pregnancy compared to women without this mutation (Gerhardt et al., 2016). The risk is even higher in homozygous carriers. However, a direct causal relationship between FVL and pregnancy complications remains inconclusive. Scholarly sources suggest that the inconsistent findings may be influenced by racial and geographic variability in the prevalence of the FVL mutation (Arachchillage et al., 2022). The absence of clear and consistent guidelines regarding screening criteria, diagnostic procedures, and anticoagulation treatment may increase patient anxiety, reduce adherence to therapy, and undermine trust in medical care (Hunter et al., 2017). This study aimed to explore the lived experiences and feelings of women diagnosed with FVL and their partners across the prenatal, perinatal, and postnatal phases of pregnancy, and to identify related psychological risk and protective factors, as well as coping strategies that support mental stability and psychological well-being.

## **2. Methods**

To capture internal psychological processes such as feelings, emotional responses, and lived-through situations, and their impact on personality (de)evolution, this pilot study employed a qualitative design using semi-structured interviews. Triangulation was originally intended through

individual and joint couple interviews, but was instead realised through analysis by two independent researchers due to limited male participation.

### 2.1. Research sample, data collection and ethical aspects

Participants were recruited through purposive sampling. Eligibility criteria included: women with a diagnosis of Factor V Leiden (either type) and an experience of a non-standard pregnancy, labour, or puerperium within the past three years. In total, the sample consisted of three female participants and one male participant, two of whom formed a married heterosexual couple. Data were collected through online semi-structured interviews. All participants provided informed consent for the interviews and were informed of their right to withdraw at any time or skip any questions they found uncomfortable.

### 2.2. Data analysis

To fulfil the study's objectives focused on lived-through experience and feelings, Interpretative Phenomenological Analysis (IPA) was employed to examine participants' emotions and understand how they made sense of their experiences, following the analytic procedure by Smith and Nizza (2021).

## 3. Results

The experiences of women diagnosed with Factor V Leiden were shaped by the course and severity of pregnancy complications. Common themes included insufficient medical attentiveness, trivialisation of the diagnosis, and a lack of information (shown in Table 1, Themes 3a–3d). For two participants, assisted reproduction and the fear of not being able to have children were central themes. In one case, this fear profoundly affected her identity and led to depression. Another participant's experience was shaped by the challenges of prophylactic treatment, including distrust in anticoagulants, discomfort with self-administration of LMWH, and fear of harming the baby.

Table 1. Cross-theme analysis - female participants.

Group Experiential Themes	Zoe	Leah	Ellen
Theme 1. Being diagnosed with the Leiden mutation	x	x	x
Theme 1a. Prior knowledge	x	x	x
Theme 1b. Learning about FVL	x	x	x
Theme 2. Navigating the fertility challenges	x		x
Theme 2a. Being on the IVF rollercoaster	x		x
Theme 2b. Becoming a mother	x		
Theme 2c. Contemplating the possibility of not being able to have a child	x		x
Theme 2d. Being depressed	x		
Theme 3. Experiencing Factor V Leiden mutation during pregnancy	x	x	
Theme 3a. Factor V Leiden mutation and pregnancy complications	x	x	x
Theme 3b. Experiencing Factor V Leiden mutation during pregnancy – (Lack of Medical attentiveness	x	x	x
Theme 3c. Experiencing Factor V Leiden mutation during pregnancy – Power of knowledge	x	x	x
Theme 3d. Prophylaxis		x	
Theme 4. Birth	x	x	x
Theme 5. Postdelivery – complications		x	x
Theme 6. Puerperium		x	
Theme 7. Summary of the overall experience	x	x	x
Theme 7a. Overall experience	x	x	x
Theme 7b. Risk and Protective Factors - Statements Synthesis and Observations	-	-	-
Theme 7c. I would have appreciated	x	x	x

Despite the emotional and physical challenges they encountered, all three women ultimately evaluated their experiences positively, largely due to the outcome of having a healthy child or children. However, their reflections also revealed ongoing needs for a more patient-centred medical approach, access to consistent and reliable information, and better availability of psychological or peer-based support. Social and partner support emerged as key protective factors, while emotional vulnerability, rigid thinking, and limited support posed risks to their well-being.

In spite of having a medical background and trusting in healthcare professionals, the male participant emphasised the value of concise, accessible information about Factor V Leiden and its associated risks to the wider population. He also mentioned preparing a backup plan in case of unexpected complications and described feeling relieved when the postpartum bleeding resolved without intervention. His pragmatic approach and emotional detachment appeared to serve as protective factors for his

psychological well-being. However, this emotional detachment also posed a potential risk of disconnection from his partner.

The couple's interview revealed that navigating complications related to FVL strengthened the relationship, enhanced communication, and fostered couple resilience. While the male participant coped through pragmatism and conversations with a friend, the female participant sought connection through online stories of women with similar experiences. These findings highlight the importance of recognising the shared emotional dynamics of couples facing pregnancy complications.

#### 4. Discussion

Most research on Factor V Leiden (FVL) and pregnancy complications is medically oriented, offering limited psychological insight. This study revealed insufficient communication and information related to FVL, aligning with conclusions by Hunter et al. (2017), who found that unclear or missing information from healthcare providers contributed to anxiety, hypervigilance, and distrust in care. One participant's discomfort with anticoagulant use and concern about harming the baby was consistent with the results of León-García et al. (2022), where women prioritised fetal safety over their own. Female participants also reported emotional distress and depressive symptoms, consistent with studies by Voss et al. (2020), who observed greater psychological vulnerability in women experiencing recurrent pregnancy loss. Social and partner support emerged as key protective factors for female participants' mental health (Voss et al., 2020), alongside optimism and goal orientation. For the male participant, pragmatism and social support appeared beneficial; however, emotional detachment also posed a relational risk, as also presented by Ruderman et al. (2020).

The limitations of this study included an insufficient theoretical saturation, insufficient male representation, limited theoretical frameworks - particularly in defining psychological terms, challenges in interview quality and IPA analysis, and possible loss of meaning in translation.

#### 5. Conclusions

This study explored the lived experiences, emotional processes, and coping strategies of women diagnosed with Factor V Leiden and their partners during atypical pregnancies. Participants reported that the diagnosis was often underestimated and noted a lack of clear information, potentially endangering both mother and child. Social and partner support were key protective factors, while depression posed a major psychological risk. These findings may contribute to improving communication practices, tailoring psychological care, and encouraging the development of peer support groups. Future research could examine how women on prophylactic treatment navigate labour decisions, particularly regarding perceived risks such as postpartum haemorrhage.

#### References

- Arachchillage, D. J., Mackillop, L., Chandratheva, A., Motawani, J., MacCallum, P., & Laffan, M. (2022, May 29). Thrombophilia testing: A British Society for Haematology guideline. *British Journal of Haematology*, 198(3), 443-458. <https://doi.org/10.1111/bjh.18239>
- Gerhardt, A., Scharf, R. E., Greer, I. A., & Zotz, R. B. (2016). Hereditary risk factors for thrombophilia and probability of venous thromboembolism during pregnancy and the puerperium. *Blood*, 128(19), 2343-2349. Retrieved from: <https://pmc.ncbi.nlm.nih.gov/articles/PMC5813719/>
- Hunter, R., Lewis, S., Noble, S., Rance, J., & Bennett, P. (2017). "Post-thrombotic panic syndrome": A thematic analysis of the experience of venous thrombo-embolism. *British Journal of Health Psychology*, 22(1), 8-25. doi:10.1111/bjhp.12213
- León-García, M., Humphries, B., Maraboto, A., Rabassa, M., Boehmer, K. R., Per-estelo-Perez, L., Xie, F., Pelayo, I., Eckman, M., Bates, S., Selva, A., & Alonso-Coello, P. (2022). Women's values and preferences on low-molecular-weight heparin and pregnancy: a mixed-methods systematic review. *BMC Pregnancy and Childbirth*, 22(1), 747. doi:10.1186/s12884-022-05042-x
- Ruderman, R. S., Yilmaz, B. D., & McQueen, D. B. (2020). Treating the couple: how recurrent pregnancy loss impacts the mental health of both partners. *Fertility and Sterility*, 114(6), 1182. doi:10.1016/j.fertnstert.2020.09.165
- Smith, J. A., & Nizza, I. (2021). *Essentials of Interpretative Phenomenological Analysis*. Retrieved from: <https://www.youtube.com/watch?v=5YM8Xxs8ucA>
- Voss, P., Schick, M., Langer, L., Ainsworth, A., Ditzen, B., Strowitzki, T., Wischmann, T., & Kuon, R. J. (2020). Recurrent pregnancy loss: a shared stressor---couple-orientated psychological research findings. *Fertility and Sterility*, 114(6), 1288-1296. doi:10.1016/j.fertnstert.2020.08.1421