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THE ROLE OF EMBODIED EXPERIENCE IN IDENTITY FORMATION IN INDIVIDUALS LIVING WITH HEREDITARY THROMBOPHILIA: INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS

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Tomán E., Pintér J.N. & Hargitai R. (2023). „A testemben szétszórt fájdalmakból kinyílott egy kis virág” – A megélt test szerepe a sternotomia heg integrálódásában egy nyitott szívműtéten átesett nőbetegnél. *Imágó Budapest*, 12(2):115-134.

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Tomán E., Pintér J.N. & Hargitai R. (2024). The embodied experience of genetic inheritance in hereditary thrombophilia. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*. — Online first.

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Indirectly utilized, first-author publications in the dissertation:

Tomán E. & Hargitai R. (2019). The psychological aspects of hereditary thrombophilia and long-term anticoagulant therapy. *Hungarian Journal of Vascular Diseases*, 26(4):93-98.

Tomán E., Pintér J.N. & Hargitai R. (2022). Exploring the Experiences of Chronic Respiratory Patients During the COVID-19 Pandemic with Interpretative Phenomenological Analysis. In: V. Komlósi A., Polonyi T. (Eds.) The Psychology of Pandemics. Budapest, Hungary: Oriold és Társai Publisher (2022) 176 p. pp. 37-42.

INTRODUCTION

In 2019, I entered the Psychological Doctoral School with specific plans and ideas. By then, I had been exploring the psychological aspects of hereditary thrombophilia for years: my thesis was on this topic, and based on a (quantitative) study, we also published an article (Tomán & Hargitai, 2019) during my university years. One of the motivations behind delving into the research gap in the examined topic was the desire to continue investigating life with thrombophilia. Another motivation was the recognition that I am not interested in numbers or proportions per se, but rather in the personal experiences hidden behind the numbers - and the answers. Thus, my doctoral research took a qualitative turn.

Regarding the structure of the thesis, the theoretical introduction begins with a comprehensive overview, which is relevant to all three studies presented, focusing on the unity and intersection points of thrombophilia, the body, and identity. However, each study is preceded by a more specific introductory section related to the particular research topic. First, we present a study addressing thrombophilia as a genetic inheritance, followed by an examination of the experiences of affected patients in the context of the COVID-19 pandemic, and finally, a single-case study illustrating the process of incorporating a sternotomy scar concludes the presentation of scientific findings. Since I worked with the interpretative phenomenological analysis (IPA) method throughout my entire doctoral process, the comprehensive theoretical introduction of the dissertation also discusses the detailed presentation of IPA as a method.

To present an essential authorial perspective in qualitative research, I strived for self-reflection throughout the research process. This process was important not only to uncover my relationship with the research but also because I participated in the research topic as an affected individual; I also live with hereditary thrombophilia. In addition to adhering to scientific ethical expectations, another important aspect of these processes was the change, alternation, and eventual fusion of two important identities: that of a thrombophilic patient and that of a researcher. The fruitful development of this fusion can be considered as significant personal growth from my own perspective.

Research questions

What identity interpretation does a genetic disease, potentially associated with life-threatening complications, provide?

How do individuals affected by severe genetic information cope with identity-related challenges? What role does the body play in all these processes?

How does the affected patient experience their body?

How does their body manifest about the disease, themselves, and their relationships with others?

In my dissertation, I seek answers to these questions.

COMPREHENSIVE INTRODUCTION

Thrombophilia refers to an increased tendency for blood clotting, which predisposes individuals to the development of some form of venous (rarely arterial) thrombosis due to a genetic defect (Sas & Kunz, 1994). In a broader sense, thrombophilia encompasses any acquired or congenital disorder of blood coagulation that predisposes to thrombosis, arising from disturbances in natural anticoagulant mechanisms. In a narrower sense, thrombophilia specifically denotes congenital conditions characterized by an increased risk of thrombosis and its recurrence, as well as their familial aggregation, even in the absence of known (acquired) risk factors (Nemes, 2000). In my dissertation, I focus on inherited (familial) thrombophilias, among which numerous genetic mutations have been identified in recent decades. Due to the large number and complexity of genetic mutations within thrombophilia, the actual prevalence of inherited coagulation disorders is not known, and available data are likely significantly underestimated. Official data suggest a prevalence of 7–10,000/100,000 individuals in developed countries (Ormesher et al., 2017; Stevens et al., 2016).

Thrombophilia's potential complication, thrombosis, can occur in any part of the cardiovascular system, including the veins, arteries, heart, and microcirculation. Severe consequences may arise locally at the site of occlusion by the thrombus (blood clot), or embolism detached from the thrombus may result in the occlusion of distant vessels. Arterial thrombosis, such as stroke or myocardial infarction, constitutes a leading cause of death in developed countries. Venous thrombosis most commonly (90%) affects the lower extremities, often presenting insidiously with subtle symptoms or, at times, with overt manifestations. Its main risk lies in acute occurrences of pulmonary embolism, which ranks as the third most common cause of death in developed countries, following the aforementioned myocardial infarction and stroke (Boda, 2014). Deep vein thrombosis (DVT) and acute pulmonary embolism (PE) are collectively referred to as venous thromboembolism (VTE). In Hungary, according to the 2008 guidelines of the Hungarian Thrombosis and Haemostasis Society, thrombosis ranks at the top of both mortality and morbidity statistics (MTHT, 2009). The prevention and treatment of deep vein thrombosis (DVT) and pulmonary embolism (PE), sharing the same pathophysiological basis, involve similar approaches, including thromboprophylaxis (anticoagulant therapy) (MTHT, 2009).

In thrombophilia, the blood coagulation mechanism is faulty, unable to perform its function properly, which cannot be removed, replaced, supplemented with something else, or cured. Thus, patients often experience a complex perception of their disease. The concept of genetic inheritance is also complex, interpreted as a problem affecting their entire lives - their past, present, and future. The genetic burden passed down by ancestors leads back to the past, while the responsibility assumed for (future) children also weighs heavily on patients (Saukko et al., 2007; Vegni et al., 2013).

Numerous studies are available on the treatment options (Al-Jabi et al., 2022; Galli et al., 2018; Von Kanel et al., 2012), prevention (Campello et al., 2019; Nicholson et al., 2020), and risk factors (Campello et al., 2019; Mannucci & Franchini, 2014; Moore et al., 2008; Van Korlaar et al., 2004; Van Korlaar, 2006) related to patients living with thrombophilia, as well as on the psychological factors concerning the diagnostic process's complex psychosocial aspects (Abughanimeh et al., 2022; Graffigna et al., 2014; Saukko et al., 2006; 2007; Vegni, 2013), and health psychology issues affecting fertility (Blickstein, 2006; Shehata et al., 2022; Unterscheider et al., 2017). However, most of these studies typically provide quantitative data and do not address the subjective experiences of the individuals affected or the potential changes in their personal identity resulting from their experiences. Furthermore, we did not find any studies specifically aimed at exploring the lived bodily experiences of thrombophilic patients.

Embodiment and Genetics

In the 1990s, the focus of health and illness sociology research turned toward genetics (Conrad & Gabe, 1999; Cox & McKellin, 1999; Parsons & Atkinson, 1992). These studies notably address the impact of genetic knowledge on life history (Lawton, 2003), identity, and family relationships (Kerr, 2004; Novas & Rose, 2000). However, the lived experience of individuals facing genetic disease may also contain a dimension revolving around the intersections of genetics and the body (Hagen, 2018). The concept of "*embodiment*" described by Csordas (1990) extends beyond the mere physicality of the body, encompassing subjective experiences intertwined with bodily phenomena, social meanings, and cultural interpretations. The advancement of genetic medicine has facilitated the formation of somatic and interdependent self-constructions among those living with genetic diseases (Kenen, 1994).

According to these studies, genetic identity formed based on genetic information largely stems from inter-embodiment experiences, in which one's own identity is closely linked to the identity of others (Hallowell, 1999). Therefore, the inter-embodiment perspective can lead to fruitful knowledge in the context of genetically inherited diseases (Jenkins et al., 2013; Oliveira et al., 2020).

Living with various genetic diseases poses difficulties and challenges for individuals in integrating inherited diseases and their potential implications into their identity. They subjectively view genetic information, and the aspects of genetic information they focus on in shaping their identity vary. Research diverges on whether genetic risk information harms self-image (Klitzman, 2009; Nordgren, 2008; Walter & Emery, 2005). Klitzman (2009) examined this issue through in-depth interviews with various individuals with genetic diseases or at risk due to their genetic heritage. Results indicate that the influence of genetics on identity is determined by several factors, including personal, cultural, and social layers of meaning attached to the disease. The integration of genetic information into personal identity can be fundamentally shaped by reactions to genetic test results and their subjective interpretation, as well as how results are communicated to family members (Oliveri et al., 2016; Oliveri & Pravettoni, 2017). Genetic risk can significantly shape individuals' self-image, leading to the development of a new self-concept due to the experience of vulnerability, such as the genetically vulnerable self (Robertson, 2000) or the "*genetically at-risk*" individual (Novas & Rose, 2000).

Interpretative Phenomenological Analysis

IPA is an interpretive, hermeneutic qualitative method. It works with an idiographic approach, aiming to uncover the rich world of meaning in experiences and perceptions (Rácz, Pintér, & Kassai, 2016; Smith, Flowers, & Larkin, 2009). Researchers employing this method are interested in the subjective interpretation of the interviewee's experiential world (Rácz et al., 2016). Due to its sensitivity, IPA can access deep experiences that may be difficult to capture with other qualitative methods (e.g., content analysis and thematic analysis). It works with theoretical and purposive sampling, as well as with homogeneous, small samples concerning the phenomenon being interpreted (Rácz et al., 2016; Smith et al., 2009). The most important theoretical foundation of this method is phenomenology, the science of experience. Phenomenology focuses on "*how experiences occur directly to individuals, how they perceive the world: objects and themselves, how they remember their past, how they experience their emotions, personal identity*" (Rácz et al., 2016:13). The phenomena to be explored in my dissertation can be fruitfully examined using the phenomenological method: how individuals perceive their bodies; what the experience of genetically determined disease means; how the experience of vulnerability and connection with others is present in the consciousness of the individuals. These are questions and experiences that phenomenology provides access to.

PRESENTATION OF THE FIRST STUDY: THE EMBODIED EXPERIENCE OF GENETIC HERITAGE

Theory and Research Questions

Our study (Tomán, Pintér & Hargitai, 2024) focused on uncovering the bodily and inter-bodily experiences of genetic inheritance. Drawing on insights from studies on embodiment experiences and family risk (Cox and McKellin, 2001; Novas & Rose, 2000; Underhill et al., 2012), we examined how interviewees perceive their genetic risk, how they negotiate family narratives, genetic legacy, and the intra-familial transmission of genetic knowledge. Through this lens, thrombophilia emerges not only as a biological phenomenon but also as a socially constructed entity intertwined with family identities, narratives, and experiences of inheritance (Rees, 2018).

In our investigation, we explored the identification and lived bodily experiences of patients with genetic risk, as well as the familial aspects of genetic inheritance. We sought answers to the following research questions:

a) What does thrombophilia, as a blood clotting disorder, mean to the interviewees?

b) How do they experience the complications of thrombophilia?

c) How do they interpret thrombophilia as a hereditary disease?

Methodology

We sought interviewees who had a diagnosis of thrombophilia and had experienced at least one venous thromboembolic (VTE) event in their medical history. This criterion was based on literature suggesting that the experiences of patients who have faced a severe, potentially life-threatening complication of thrombophilia differ significantly from those who have not yet encountered such an event (Saukko et al., 2007; Vegni et al., 2013). In all cases, the VTE event preceded the diagnosis of thrombophilia. We conducted a total of 10 interviews, with 9 women and 1 man. The focus points during the interviews were: experiences of thrombophilia as a genetic disease, the bodily experiences of the disease, the diagnostic process, and the experiences of familial/transgenerational inheritance. The study was conducted with the ethical approval of the Scientific and Research Ethics Committee of the Health Sciences Council (ETT TUKEB): 46496-4/2019/EKU.

Results

In analyzing the interviews, we focused on the embodied experience of genetically inherited thrombophilia. Within this context, three common experiential themes emerged: The Body as a Repository of Risk (1), Family Heritage (2), and The Borderland of Thrombophilia – Liminality (3).

Discussion and Conclusions

Our study found that patients living with thrombophilia perceive their bodies as repositories of genetic risk. In connection with this, the discourse of familial risk also emerges, which proved to be particularly fruitful in studying family dynamics and beliefs. For individuals facing thrombophilia and its risks, the disease represents an intersubjective process that can provide meaning during the processing and integration of genetic risk information.

Adapting to thrombophilia seems to involve the significant creation of a genetically at-risk identity. Alongside these new identities, living with the risk can also induce newly discovered forms of genetic/familial responsibility within the shared experience of family history and inheritance.

Our research indicates that individuals living with thrombophilia experience the borderland of liminality. In certain cases, however, the space between health and illness represents a dynamic permeability (Boardman & Clark, 2022) for those with thrombophilia. The dynamic movement between these two states can be triggered not only by personal experiences and life events but also by medical uncertainty.

From the perspective of understanding the experience of thrombophilia, the embodiment perspective can be a tool that supports patients in moving away from conventional social and cultural norms through the expression of an alternative body experience. The combination of the embodiment paradigm and the phenomenological-hermeneutical perspective has surfaced a deep experiential layer, previously known only to those who lived it as a kind of silent companion (Wilde, 2003). The physical risks present additional challenges (Kavanagh & Broom, 1998): the parallel presence of the disease in the past, present, and future; the long-term necessity of drug therapy; an increased tendency for dissociation between the body and the self; and the lack of social discourse and linguistic expressibility.

Understanding the psychosocial dimensions of embodiment in thrombophilia has significant implications for patient care and public health interventions. With this knowledge, healthcare professionals can provide more holistic and patient-centered care that addresses not only the physiological aspects of thrombophilia but also the psychosocial dimensions of living with hereditary risk. Further research is needed to delve deeper into the underlying motives of liminality, the responsibility associated with inheritance, and the embodied experiences of long-term anticoagulant therapy.

Limitations

The limitations of our study are primarily related to the constraints of the Interpretative Phenomenological Analysis (IPA) method, such as the small, homogeneous sample, the topic-specificity, and the difficulty in establishing connections and generalizations (Smith and Nizza, 2022). These are, however, methodological characteristics rather than specific limitations of this research. As qualitative researchers, our choice of method was not accidental; the IPA method allowed us to access the unique and profound experiences of our interviewees, thus enabling us to understand and comprehend the burdened experience world of the affected patients. The homogeneous sample contributed to this, as a methodological characteristic of IPA is the examination of as homogeneous a sample as possible, thereby facilitating a more comprehensive understanding of a particular experiential world.

PRESENTATION OF THE SECOND STUDY: THE EXPERIENCE OF THROMBOPHILIA DURING THE COVID-19 PANDEMIC (Tomán, Pintér & Hargitai, 2022a;b; 2023a)

Research Objectives and Research Questions

Our study sought to investigate and deepen our comprehension of the experiences and perceptions of vulnerability among thrombophilia patients who have encountered pulmonary embolism amidst the COVID-19 pandemic, employing interpretative phenomenological analysis. We sought to answer the following research questions:

a) How do the interviewees relate to their previous experience of pulmonary embolism in the context of the COVID-19 pandemic?

b) What does the experience of vulnerability mean to them?

c) How do the original experiences related to their underlying condition affect their perception of vulnerability during the pandemic?

Procedure

Data collection for the research took place from June 2020 to December 2020, during the first and second waves of the coronavirus pandemic. The study was conducted within the framework of the ELTE Faculty of Education and Psychology Qualitative Research Group's research project titled "*Examining the Experience of Individuals in Social Isolation During the COVID-19 Pandemic*." The research was approved by the ELTE Faculty of Education and Psychology Research Ethics Committee, with approval number: 2020/315.

Methodology

In the first part of this study, we examined the experiences of a less homogeneous population, specifically patients living with chronic respiratory diseases (Tomán et al., 2022a; 2023a). A total of 8 interviewees participated in this study, of whom 2 had a history of thrombophilia and pulmonary embolism, while the other 6 suffered from other types of respiratory diseases (COPD, cystic fibrosis). Since we aimed to conduct this research with a more homogeneous group, specifically patients with thrombophilia who had experienced pulmonary embolism, we conducted a second set of interviews focusing on the relevance of COVID-19 with those previously involved in the first doctoral study who had a history of pulmonary embolism (4 individuals). In this second part of the COVID-19 research, a total of 6 participants were involved. This number complies with the requirements of IPA (Smith et al., 2009), although it is at the lower end of the expected range. The complexity of the inclusion criteria made recruitment challenging despite the two-step data collection process. The population with pulmonary embolism was crucial for several reasons discussed in the introduction: firstly, having a respiratory condition likely caused significant anxiety related to the potential threats posed by COVID-19 to the respiratory system, as demonstrated by our research (Tomán et al., 2022a; 2023a). Secondly, subsequent studies indicated that patients who contracted COVID-19 were more likely to experience damage and complications affecting the lungs and respiratory system, including pulmonary embolism (Bikdeli et al., 2020; Gkena et al., 2023; Suh et al., 2021).

Results

The analysis of the interviews revealed 2 main experiential themes, each with 2 sub-themes, which were analyzed within the context of the lived body. The structure of the themes, along with the corresponding quotes, is illustrated in Figure 1:

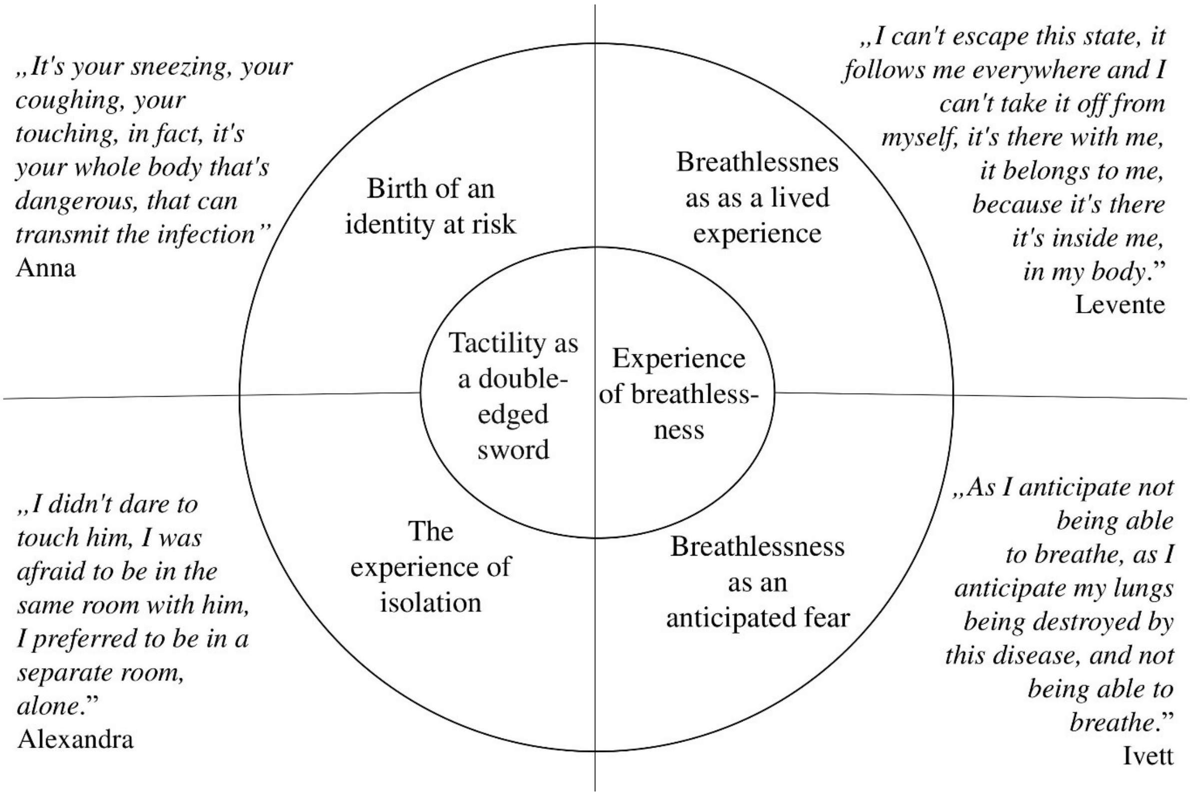


Figure 1.: The results of the second study.

Discussion and Conclusions

During the period surrounding COVID-19, the interviewees uniformly perceive themselves as vulnerable, and experiencing this vulnerability fundamentally shapes their lives, decisions, connection to their bodies and the world, and identity formation. The threatened identity affects multiple levels of identity as a system and can be understood as an internal conflict arising from the collision of different identity parts (Breakwell, 1986). Awareness of risks induces anxiety among those affected (Csabai & Erős, 2000): experiencing the threat to health, and thereby to the body and life, challenges their belief in the safety of the world, even alongside their positive self-esteem and self-identity.

Due to the coronavirus primarily affecting the respiratory system, patients with respiratory diseases or those who have suffered respiratory damage unanimously perceive themselves as vulnerable due to their physical conditions, projecting severe consequences related to infection—primarily the experience of breathlessness. The reason for this negative anticipation lies partly in their past experiences, which include severe symptoms communicated concerning COVID-19 (such as difficulty breathing, suffocation, lung damage, intensive care, and mechanical ventilation). Visual sequences often shown by the media depicting intensive care treatments can trigger severe retraumatization in some patients. In the experience of retraumatization, we essentially see the inseparability of external and internal threats manifesting, where threats that once came from outside become internalized through experience and later determine the dynamics of identity even without the concrete presence of the threat (Breakwell, 1986; Serdült, 2015). A severe crisis can also challenge an individual's sense of continuity, as it disrupts the psychological chain between the past, present, and future (Murtagh, Gatersleben & Uzzell, 2012); the traumatic past becomes the present, and the future becomes an expression of negative anticipation. This negative prognosis for the future narrows the patients' entire world (Toombs, 1993).

The potentially infectious nature of COVID-19 creates a sharp boundary between the vulnerable Self and the dangerous Other, placing a distinct line between the Self and the outside world. Our existence is fundamentally determined by our connection to others, which has an undeniably physical dimension: being with another person cannot be complete if it happens remotely, without the physical presence of two bodies, virtually; nor can it be fulfilled if it is permeated by fear (Carel, 2020). This unfolds in the accounts of the interviewees when they meet their loved ones in the virtual space forced upon them by isolation, and also when they speak with deep fear about their feelings towards people regarding touch, the tactile interaction essential in human relationships. The experience of the COVID-19 pandemic forcibly brought people back to their bodies—both in the context of sensory awareness and proprioception (Dahiya, 2020). This research utilizes this return to the body to examine how the pandemic has transformed relationships with the body. The significance of infection, the fear of being infected, and isolation from significant others prompts a confrontation with the phenomenological and embodied experience of touch—and its significance (Dahiya, 2020).

The pandemic represents a particularly critical situation in terms of the fulfillment of social needs and desires. Social distancing involves significant loss, not only in terms of the transformation of routine activities and social relationships but also in the disruption of connections with familiar, stabilizing spaces and places (Jaspal & Nerlich, 2020). This latter experience is represented by the absence of regular check-ups and the disruption of the personal, physical relationship with the attending physician, who serves as a significant other providing a sense of security.

The potential danger of infection brings us back to our bodies, but it does so burdened with the feeling of fear. Our corporeality becomes apparent to us through fear, prohibitions (Dahiya, 2020), and previously lived and unresolved experiences of embodiment trauma (Tomán et al., 2023a). The pandemic has challenged our lived experiences related to our bodies and senses. The threat of infection, or the lived experience of the COVID-19 pandemic, strongly evokes the rediscovery of the world of bodily perception. COVID-19 is both a virus and a connection, prompting us to focus on care and social relationships – the embodied histories of these relationships (Shotwell, 2020).

Limitations

One limitation of this study is the two-phase data collection process. We conducted interviews with four out of the six participants on two occasions to include the subjects from our previous research in the study examining COVID-19-related experiences. It would have been preferable to conduct all interviews either exclusively during the first or the second wave of the pandemic, as there might have been changes in the participants' experiences between these periods. Another potential limitation is the possible lack of the expected homogeneity in IPA studies, as the interviewees had varying severities of pulmonary embolism in their medical histories. Significant differences might arise in the experiential world between those who have experienced a high-risk pulmonary embolism and those with a lower-risk condition.

PRESENTATION OF THE THIRD STUDY: "*A LITTLE FLOWER HAS BLOSSOMED FROM THE PAINS SCATTERED IN MY BODY*" – THE ROLE OF THE LIVED BODY IN THE INTEGRATION OF THE STERNOTOMY SCAR IN A WOMAN WHO UNDERWENT OPEN-HEART SURGERY (Tomán, Pintér & Hargitai, 2023b; c)

Theoretical Background and Research Questions

Median sternotomy refers to the longitudinal incision made along the midline of the sternum, a standard medical procedure for open-heart surgery. This procedure provides the most commonly used access to the heart for surgical interventions. The sternotomy scar serves as a painful reminder of the traumatic experience surrounding open-heart surgery and the long recovery process that follows. The formation, healing process, and symbolism of a scar play a significant role to the body and bodily experience. Various causes can lead to scar formation:

burns, accidents, diseases, and surgeries. What they share in common is that these injuries leave a mark on the body (the skin), signs that may fade over time but never completely disappear (Linares, 1996).

In the perception of the patient, heart surgery is a matter of life and death, as the heart is associated with the experience of existence – non-existence, emotions, and the 'engine' that powers the body (Buckle, 2005; Tordai, 2005). Thus, it evokes deeply existential questions. Open-heart surgery is potentially a traumatic experience for patients (Stoll et al., 2000; Callus et al., 2020; Tigges-Limmer et al., 2021), posing a real threat to the patient's physical and mental health and bodily integrity (Gorven & Plessis, 2018), which can significantly influence the emotional relationship to the scar and the bodily aspect of self-representation (Kantoch et al., 2006; Adib-Hajbaghery et al., 2020).

A scar is a lasting mark of past bodily experiences, thus representing the past while also embodying the present internal world of the person in the reflection of their relationship to their body (Szemerey, 2019). The traumatic experience is etched into the skin, meaning these scars come with noticeable bodily changes (Kantoch et al., 2006; Adib-Hajbaghery et al., 2020). There is limited literature available on post-operative experiences involving median sternotomy (Crossland et al., 2005; Kantoch et al., 2006; King et al., 2008). However, it is established that patients report a loss of femininity, dissatisfaction with their appearance, compromised body integrity, reduced sexual attractiveness, and dissatisfaction with the scar, experiencing their bodies as wounded entities, disfigured from their previous characteristics (King et al., 2009).

The development of a heart surgery rehabilitation and peri-operative protocol based on the embodiment paradigm is still awaited, despite numerous studies emphasizing the necessity of competent cardiac rehabilitation (Khoshay & Shasavari, 2013; Tigges-Limmer et al., 2021; Tulloch et al., 2015; Younes et al., 2019).

We sought to answer the following research questions:

a) What significance do the median sternotomy scar and the surgery itself hold for the affected individual?

b) How are the two examined entities – the scar and the surgery – related to each other?

c) How and in what way can the scar become part of one's identity?

Procedure

This study has been approved by the Scientific and Research Ethics Committee of the National Institute of Health (IV/3324-1/2022/EKU). Data collection took place in the autumn of 2021 in the form of two semi-structured interviews conducted at different times. The participant – let's call her Eszter – is 42 years old, married, and the mother of an 8-year-old boy. At the time of the interviews, she was preparing for her second open-heart surgery. She had her first heart surgery at the age of 30 due to a congenital valve abnormality. The surgery and the underlying condition were complicating factors in her decision to have children.

Methodology

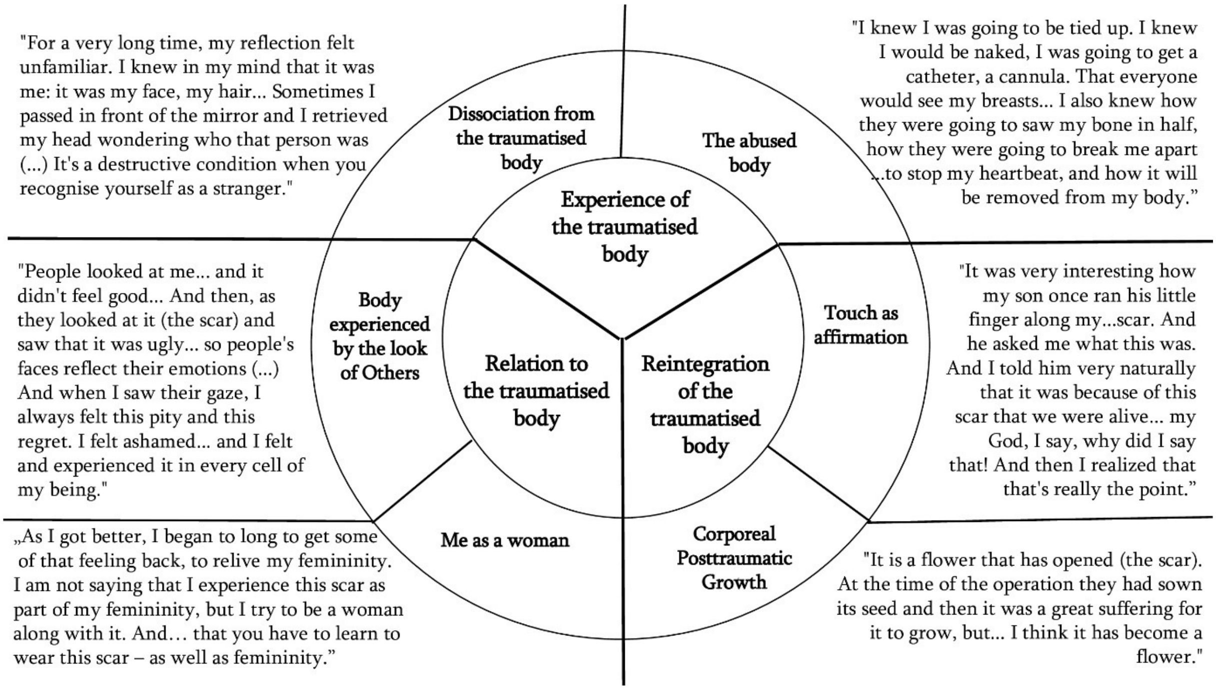
The data collection phase of the study consisted of three parts: the first step was a semi-structured interview, the second involved creating projective drawings, and the third step was conducting the second interview, also semi-structured, following the principles of IPA methodology. Three weeks elapsed between the first and second interviews. The questions and structure of the interviews focused on allowing the participant's general opinions and attitudes towards the research topic to be expressed, followed by a freer exploration of interpretations, experiences, and attitudes related to the sternotomy scar and the underlying condition, with an emphasis on lived bodily experiences where possible. The interviews covered the following themes and questions: the experience of open-heart surgery; changes experienced in life due to the surgery; the experience of encountering the scar for the first time; emotions and relationship with the scar; changes in the relationship with one's own body throughout the course of the illness; experiences in social relationships. At the end of the first interview, the participant was asked to create the two projective drawings, with clear instructions given for each. Additionally, it was communicated that any drawing tool could be used according to their preference. The participant sent the drawings to me electronically after completing them, and then we scheduled the time for the second interview. During the second interview, the participant was asked about their experiences and reflections during and after the first interview, then we moved on to discuss the drawings. They were asked to talk about their experience of drawing, describe how the drawings relate to the scar and their feelings about their body. The first interview lasted 1 hour and 55 minutes, while the second interview lasted 55 minutes.

Instructions for creating the drawings:

1. *Please draw yourself after your heart surgery*!
2. *Please draw your heart surgery scar as you see it*!

Results

The main and subthemes of the unfolding personal experiences are presented in Figure 2.



"For a very long time, my reflection felt unfamiliar. I knew in my mind that it was me: it was my face, my hair... Sometimes I passed in front of the mirror and I retrieved my head wondering who that person was (...) It's a destructive condition when you recognise yourself as a stranger."

"I knew I was going to be tied up. I knew I would be naked, I was going to get a catheter, a cannula. That everyone would see my breasts... I also knew how they were going to saw my bone in half, how they were going to break me apart ...to stop my heartbeat, and how it will be removed from my body."

"People looked at me... and it didn't feel good... And then, as they looked at it (the scar) and saw that it was ugly... so people's faces reflect their emotions (...) And when I saw their gaze, I always felt this pity and this regret. I felt ashamed... and I felt and experienced it in every cell of my being."

"It was very interesting how my son once ran his little finger along my...scar. And he asked me what this was. And I told him very naturally that it was because of this scar that we were alive... my God, I say, why did I say that! And then I realized that that's really the point."

„As I got better, I began to long to get some of that feeling back, to relive my femininity. I am not saying that I experience this scar as part of my femininity, but I try to be a woman along with it. And… that you have to learn to wear this scar – as well as femininity."

"It is a flower that has opened (the scar). At the time of the operation they had sown its seed and then it was a great suffering for it to grow, but... I think it has become a flower."

Figure 2.: The results of the third study.

Conclusions

The formation, healing process, and symbolism of a scar hold a significant role in bodily experience. The core of the traumatic experience of open-heart surgery revolves around the perceived attack on the patient's bodily integrity. The interviewee perceives the surgery as violence inflicted upon their body, leaving a deep imprint in both bodily memory and in the form of a scar on the skin. Based on our study, it appears that the traumatic experience of heart surgery may pave the way for the development of the bodily dimension of post-traumatic growth. In this process, tactility and intimacy play a fundamental role, allowing for a sensitive (bodily) rediscovery of oneself and the affirmative touch of significant others. An important conclusion of our study is that the relationship with the scar as an independent entity can facilitate understanding of one's relationship with the traumatic experience that caused the scar.

Based on our research, we can conclude that the creation and interpretation of drawings are important components of constructing one's own narrative, integrating body image and self-image. Artworks depicting the body can lay the groundwork for individuals to connect with their bodies and engage in the process of finding meaning. Therefore, it is certainly worth supplementing body-centered work with art therapy sessions, as, in the words of Johnson (1987:13), "*Art was probably originally a means of expressing and mitigating traumatic experience.*"

Limitations

In addition to the limitations of previous research, another limitation of the present study is that from a scientific perspective, the theory of embodiment is easily criticized, as it is difficult to support scientific methods. However, as an advantage of our research, we consider the access to unique and profound experiences, particularly with the integration of drawing analysis into the interviews, which has enabled us to access a particularly rich and deep body of knowledge that may not have been accessible through other methods.

COMPREHENSIVE DISCUSSION

My dissertation was intended to present the physical experiences of patients with thrombophilia and the complexity of this disease through the accounts of the patients themselves. The overall summary and discourse of the three research studies were presented unusually through the inclusion and perspective of an area that I considered essential to the overall thesis and research series. This area is the closely interrelated phenomenon of the bodily unconscious and traumatic body memory, the relevance of which for this thesis emerged in the course of my interpretation and comprehensive review of the entire research process.

I present the path to the bodily unconscious and traumatic bodily memory along four important conceptual aspects of Fuchs (2012; 2019), based on Ullmann's (2022) division: 1. the difference between possessing the body and existing as a body; 2. being in the bodily world as the extra-psychic existence of human existence; 3. bodily memory; 4. the bodily unconscious. The difference between possession of the body (Körper-Haben) and being as a body (Leib-Sein) was first described by Plessner (1970), a statement which essentially complemented the Leib - Körper distinction of Husserl (Husserl, 2000), which had been explained earlier. Fuchs drew primarily on Plessner's (1970) distinction, for in the relation of possession, besides the external character of the body, a cultural tendency is also evident, characterized by a kind of body-forgetting (Böhme, 2003). According to this, the state of being as a body (the extension of the Husserlian Leib) is permanently suppressed, overwritten, or distorted by the state of possessing the body (the extension of the Husserlian Körper), since we feel secure when we can possess or are considered to possess our body as a Körper, i.e.

our body used as an object - repaired, beautified, maintained. We see this manifested in the accounts of our interviewees as they convey, at length and laden with painful emotions, their experiences of the signs, the decay of their dissociated bodies, the object of their hatred and fear - and the risks they carry in their bodies. Through control, visual monitoring, blood tests, and drugs, they feel they own their bodies: their symptoms, their complications, and their (genetic) risks.

In our study, the phenomenon of the family corpus (Novas & Rose, 2000) has unfolded, offering an important interpretation of genetic disease for those affected. The question arises whether, in the case of a genetically inherited disease, the (traumatic) experience of a common disease can be interpreted through the family unconscious or the family body memory. The family unconscious is a form of the external unconscious, which is different from the concept of the body unconscious, which is one of the focuses of the present discussion, and which is not an intrapsychic phenomenon, but is not located in interpersonal relations, but in the subjectively experienced space of the person (Ullmann, 2022). However, it is important to mention body memory to understand the body's unconscious.

Already in the 19th century, Bergson (2007) examined the habitual capacities of the body as a specific memory system and distinguished between memory-image and habitual memory. For us, the most relevant information from Bergson's findings relates to habit-memory, which "*does not represent the past, but re-enacts it*" (Bergson, 2007:87). That is, the experience of retraumatization that unfolds in several cases in our study is not manifested as a re-enactment of an intensional experience of the past, but in these cases, habit-memory enacts the past. When the interviewee reports a panic-like experience of paralysis that erupts from her at the sight of a patient on a ventilator, her habitual memory is triggered, resulting in the enactment of the experience that she has stored in her body.

Painful experiences are not only recorded as memories, but also deeply imprinted in bodily memory (Stupiggia, 2016; Van der Kolk, 2014). This seems to be manifested in our interviewees' accounts, where their bodies often react to a situation they perceive as dangerous before they consciously start to move away from it: they start to feel frightened, sweat, pant, feel pressure in the back of their neck. We know that the memory of the trauma recedes from conscious memory, yet it remains vivid and effective at the level of the experienced body as if it were some kind of alien body that appears involuntarily in certain situations - and in the same way as it did in the original case (Fuchs, 2012; Stupiggia, 2016; Ullmann, 2022; Van der Kolk, 2014). In a sense, trauma is more vivid in bodily memory than in pictorial or intentional memory (Ullmann, 2022). The experience of a painful experience, the bodily suffering experienced through illness, the experience of breathlessness, and the experience of shame resulting from a body lesion may be confused and vague at the level of cognitive memory, but the body may remember immediately in a situation similar to the previous one and react to the memory of the trauma with a variety of symptoms (Stupiggia, 2016; Ullmann, 2022). Appelfeld (2005) describes traces deeply imprinted in bodily memory that may be more profound and persistent than biographical memory - bodily sensations, impressions, and perceptions that may mediate sudden and unexpected re-enactments of the past. This re-enacted past is not in cognitive memory, but in the body (Ullmann, 2022).

The body, or more specifically the skin, or the "*skin-self*" (Anzieu, 1991), is not only present in the experience of our interviewee with a cardiac scar as a protective wall of the subject but also as a manifestation of memory. The meaning of the traumatic experience of the surgery is incorporated into the scar - the scar is incorporated into the subject. This may also mean that the exploration of the relationship to the scar as an entity in its own right can support an understanding of the relationship to the traumatic experience behind the scar's genesis. Indeed, the interviewee does not only relate to the scar as a physical entity but also explicitly experiences the feelings contained in the experience of her body. This experience supports the possibility of reworking traumatic memories stored in bodily memory. Our study thus suggests that a patient who has lost bodily integrity may be able to reconstruct the self through the potential of bodily memory. The body, which is a symbol of the traumatic experience, is a trigger for the interviewees to recall painful memories: proprioception, tactility, smell, and hearing can activate past events. Bodily memory is "*a somatic echo of the memory traces of lived experiences and a condition of possibility for opening up to the world*" (Horváth, 2019:38).

At this point, we come to the phenomenon of the bodily unconscious, which refers to the particular schematization of our experience of being in the world (Ullmann, 2022). It is not the result of repressions, as in psychoanalysis, and is therefore not a vertical phenomenon, but a horizontal one (Fuchs, 2012; 2019). It takes the form of reactions that trigger intense and violent emotional processes, during which the experiencer does not know or understand why this is happening to him. His intense experiences are constituted as alien realities (Ullmann, 2022). Fuchs does not claim that his theory is the only valid conceptualization of the unconscious but merely suggests that, alongside other universally known types of unconscious, the phenomenon of the bodily unconscious should be considered in clinical work (Fuchs, 2019 cited in Ullmann, 2022).

COMPREHENSIVE CONCLUSION

During the years of my doctoral process, I have learned a lot about the body of the chronically ill person - both psychologically and phenomenologically. And I feel this knowledge is relevant and important because I see the way to their mental state, to adequately support and help them with their difficulties and problems in psychological discourse, is through their body - their lived bodily experiences. In my dissertation, I have presented the body and the body-identity relation system, and I have also presented the theories, both known and little known, in psychology and the phenomenological paradigm. To add complexity and nuance to this, I have presented the multiple lived experiences of people with thrombophilia in three different research studies, from three different perspectives. As can be seen, this nuance may be due to the thousand-faced nature of this disease: it is a potentially fatal condition, yet some people remain asymptomatic for the rest of their lives. There are, however, those who have to deal with several serious and traumatic complications throughout their lives - and their medical history. Some bear the mark of these complications on their body for the rest of their lives, and others live with the invisibility of thrombophilia. What they all have in common, however, is that they bear the birthmark of the disease, a family inheritance that they have received but never asked for, from birth until death.

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