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Psychological Treatment of Endometriosis and Support in Coping with the Disease

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1. Introduction

Endometriosis is still a mysterious disease that afflicts affected women during their fertile years. In fact, the disease can appear as early as the first period and menopause may not relieve the symptoms. (Rogers et al., 2009).

The leading symptom of endometriosis is chronic pain, which is mostly localized in the lower abdomen, the pelvic area, but can also radiate to the waist. Relieving pain symptoms is the main motivation for women with endometriosis to see a doctor. (Siinai et al., 2007)

> It is an interesting fact that the degree of pain is not necessarily related to the size and extent of the endometriotic nodules.
> Fertility disorders, difficulty conceiving, is the second most common reason for women to see a doctor. It can be assumed that endometriosis can cause fertility difficulties both mechanically (by adhesions, tubal occlusion, etc.) and by inhibiting ovarian migration, fertilization, and implantation (Van den Broeck et al., 2013). Difficult conception and possible complete infertility are symptoms that are also worth mentioning from a psychological point of view, as they greatly affect the self-esteem, coping ability, and relationship dynamics of those affected.

The disease affects 10–15% of women of childbearing age and 3–5% of women after menopause. So it can be observed that at least one in 10 women is affected, so there are about 176 million women around the world suffering from this disease (Árvai, 2012).

The establishment of a diagnosis often lasts for years: an average of 6-8 years, and an average of 8 doctors take part in providing the diagnosis. Rolling up a wide range of symptoms can in many cases put patients on a long patient career path until one remembers that organ-specific complaints are associated with the menstrual cycle. By the time patients are diagnosed, they are often exhausted, frustrated, and because they have countless completely negative findings from many places, they eventually believe that we only have the problem in our "head" (Árvai, 2016).

Endometriosis can negatively affect the quality of life, relationships, sex life, and ability to work of affected women. Patients are more likely to report anxiety, worries

about the future, and are more likely to experience depression, mood disorders, and often strong guilt.
The following case study provides an insight into my psychological work with a woman with endometriosis.

2. Case Study

For ethical reasons, the case presented below was compiled by belnding 3 similar cases. Maria's story is a good example of the importance of health psychology and health sociology in practical helping work.

2.1. The source of the request

Maria is a thirty-eight-year-old, restrained-looking woman who is a little embarrassed when we first met, but she became more relaxed soon. The first problem to be addressed in the interview is that she feels worthless as a woman. She is often anxious, and she is also suffering from the tension associated with fertility difficulties. Although she made her appointment through the online reporting system, both her family of origin and her partner welcomed her decision.

2.2. Encounters with the client and the problem as the client presents it

During the encounters with the client, of course, the story is constantly forming and her goals are changing too. Maria is married. She reports anxiety and depressive symptoms, the cause of which is that her ovaries have been destroyed on both sides due to her illness, one has been removed and the other is impenetrable, so she is forced to resort to assisted reproduction. She had a hard time processing it, she showed signs of anxiety, she folded her hand, bit the edge of her mouth, she even cried once.

The disease – stage III endometriosis – was revealed during laparoscopic surgery, which was performed because she had wanted to get pregnant for two years, but she tried unsuccessfully. Maria's doctors said she had no chance of conceiving naturally. She was very scared of the fresh diagnosis, she wanted to get help to prepare for the IVF program, which she was quite wary about at first.

She said it is very difficult for her to accept that she cannot get pregnant spontaneously. She was afraid of the side effects of the IVF program. She heard and read a lot of bad things, from the recurrence of endometriosis to the risk of breast cancer later. Infertility has a serious negative effect on female self-esteem, so women with endometriosis often see the disease as a constant threat, a kind of time bomb that can reappear at any point in their lives. In the case of Maria, all these difficulties arose. She also feared that the IVF program would take away the romance of expecting a child and ruin her relationship. She felt embarrassed to get pregnant with IVF because it meant she was unable to function properly as a woman.

In Maria's case, it was important to assess the level of prior knowledge about the disease, to gently correct incorrect/excessive information, to educate patients, and to teach them how to use the forums and groups available on the Internet in a way that benefits them, not just "The sad stories drag her down." She read that the Catholic Church had a rejective opinion about the IVF procedure and therefore did not know how to tell her parents about the problem because they are faithful Catholics.

The situation was aggravated by the fact that shortly after our first conversation, excerpts of an interview with a highly respected church official appeared in the news according to which the IVF program was a sin that should be eliminated. These articles shattered Maria and while she was speaking about this, her voice was trembling, on the verge of breaking down in tears repeatedly. She called herself a "flawed" woman, struggling with guilt, fearing that due to her fault they would not have a child, and couldn't imagine what other meaning could be found in life if someone did not raise a child.

In addition, she felt left abandoned by the health care system. She said she never had the opportunity to ask questions from the doctors, was treated on a treadmill, paid tens of thousands for five minutes she spent in their offices, with doctors who said he saw only the bill she'd pay, not a young woman yearning for reassurance. She did not dare to share her worries with her husband because she was afraid that Peter would mentally collapse then, and she would no longer be able to bear it if she saw her husband suffer because of her illness and its consequences.

Maria's typical way of thinking was catastrophizing. Everyone encouraged her that even the first IVF could be successful because her uterus had a healthy hormonal household. For her needing an IVF already meant that she would probably never have a child, was worthless as a woman, she was alone with her worries Her husband could leave her any time once he realizes this is her "fault".

An important element of our initial conversations was a kind of education, in which I provided real, credible information about the nature and course of the IVF program and the real data on possible side effects because, in the vast majority of the Internet, I encountered negative stories. I passed the information to her by sitting down, leaning back, offering her a seat, too, and asking her to put questions that keep bothering her that she hadn't had a chance to ask before. This ensured that we had time to talk to each other. She later said she felt that now we didn't have to stop as long as she had unanswered questions about IVF. That was very good for her, so we were able to overwrite her previous bad experience with the way too busy medical staff. We also discussed in detail exactly how the IVF program works and thereby transformed the exaggerated ideas in Maria's mind that mystify the process. We also talked about an IVF being neither a panacea nor a child producing factory. According to Maria, one sentence was very important for her which was that if a sperm did not want to "stay" in the ovum, it would not, not even during IVF, so this was not "rape" against nature, just a little help for the cells when they want to meet, but they cannot because of the inadequacy of the physical conditions.

The cold terms of stimulation, suction, fertilization, implantation were renamed the rendezvous of the cells, which helped Maria find the missing "romance" in the process. In this way, we managed to frame the IVF program itself from a violent, aggressive process to a helpful, beneficial process that would help Maria to become a mother.

2.3. Relationship with the Client

Fortunately, Maria had no trouble talking about her thoughts with someone who was not religious herself. This is a very sensitive topic that requires increased care on the part of the helper. It builds a relationship of trust between the psychologist and the client, establishes the rapport when we can talk honestly about this helping relationship. It was reassuring for Maria that we exchanged a few sentences about this. It is the individual decision of the professional helper to decide how much and what kind of information to share with the client about themselves, and this is sometimes an intuitive process.

In the case of Maria, these few sentences strengthened her confidence and especially thanked me for my sincerity. She said it was like an invisible wall had fallen between us. It was even important to her that I was willing to "take a step" and confirmed that I imagined that if there is a God, I think God is very happy that IVF exists because for God life is the greatest value. Life is at the end of the process and God's blessing also accompanies this process. I have tried to deal with religious issues very carefully throughout our nine consultations and there was only one occasion when we were discussing these issues.

2.4. Summary of Applied Techniques, Tests, Results of Other Examinations

2.4.1. Coping Skills, Resource Mapping

The Body Sculpture Test was one of the first tests we did with Maria. This test was validated in Hungarian by Fehér Pálma and used in somatic patients (Fehér, 2013). She formed a fragile, thin, recumbent human figure out of clay. She worked rough, fast, almost in a hurry. She finished it soon. She carved three lines on the face of the two eyes and the mouth with her fingernail in a recumbent shape and punched three tiny holes in the abdomen, illustrating the traces of endometriosis surgery. The belly of the recumbent figure was convex, she looked like she was pregnant, but when Maria tried to set up the figure –the figure was lying when she was shaping it but it was originally intended to be a standing figure – she almost angrily emphasized that she was not pregnant, just bloated because of endometriosis. The statue was unstable, it couldn't be made stand up and Maria couldn't even let it go, because one or another limb fell of it whenever she tried. She repeated it for a couple of times and then became so angry that she threw it all in the trash, saying this is how much the figure was worth "Just like me…"

Maria showed a lot of anger towards herself and her body at first, she felt that she had failed, and her body had let her down. She also felt anger toward doctors who did not realize in time that her infertility may be due to endometriosis. It only added to her frustration and distrust of the medical staff that she felt she had not been properly cared for. The medical staff left her with unanswered questions.

We discussed who the ideal doctor would be, whom she could trust, what qualities the doctor should have. What aspects were important to her, and what wishes she would be willing to enter a compromise on. Based on these, the doctor who made the diagnosis did not meet Maria's expectations, but an important moment was the discovery that she did not have to remain defenseless, and the control over the choice of institution and doctor was in her hands. There is no point in rushing the process, nothing happens if she starts the program a month later, once the right location and support staff have been found.

I used direct suggestions to describe her near-future situation, instead of "if" I said "when you found the right doctor", and so on (Varga, 2013). I was aware that "finding the right doctor, the right institution" could potentially lead to a time-consuming run from doctor to doctor, not being able to commit oneself, but for Maria, this was out of the question: she did her research for a doctor, went directly to the doctor she had chosen, and she had a very good first consultation with her indeed. Finding the helper she trusted increased her ability to accept the situation.

We often went back and forth in our conversation to verbalize her goals, that her greatest desire was a baby, and that the IVF program is the only way to achieve this goal of hers. We formulated and stated what the purpose of the procedure was and why it was good for her. In addition to the goal-setting, we also used the method of positive visualization, I made her imagine herself pregnant with a baby, and then as a happy mother of it. I asked her to imagine how it feels to hold her baby in her arms, and her face lit up while she was imagining her dream. I said then that experience has shown that when she'll hold this soft, sweet-scented, sniffling baby in her arms, her baby, she won't even remember whether that it had been conceived in an IVF or spontaneously, it won't matter at all.

For Maria's difficulties sleeping problems and her anxiety complaints, even the simplest methods proved to be sufficient: she developed an evening routine that included logging her feelings and thoughts, sipping her favorite stress-relieving herbal tea, refreshing her old-fashioned autogenic training, refreshing her memories. We also included some simple breathing and relaxation exercises in our self-reassuring techniques (abdominal breathing, complete yoga breathing, progressive muscle relaxation, conscious walking).

I only had meetings with Maria nine times. These occasions assisted her to become much calmer, more optimistic, more balanced, looking forward the IVF program with excitement, surrounded by helpers she trusts. She no longer sees the process as something devilish, but as an opportunity that will help her become a mother.

In the case of patients with endometriosis and fertility disorders, it is often necessary to have a systemic approach, in which the involvement of the family and the couple becomes necessary. For one of the nine meetings, I also invited her husband, Peter, to assess the extent of his support as a partner and the dynamics of their relationship.

He gladly accepted my invitation because he also had some questions about IVF, he was afraid of the effect this procedure could have on his wife. He was reassured when he received the necessary information that he had lacked, so education and information transfer played a key role here as well. I have witnessed Maria dare and be able to talk to her husband about her feelings about IVF. She found a good partner in Peter, I have confirmed to them what a good team they are.

The PRISM-D drawing test of the client is attached. The advantage of the PRISM-D drawing test is that it can be used quickly and easily to map the client's disease representation and coping factors. Visual representation of the current life situation expects activity from the client, facilitates conversation with the support staff, and helps to look at the current situation more easily, self-reflection. The test recording can be repeated several times so that we can track the changes and the progress (Havancsák et al., 2013).

The drawing shows a so-called self-shield constellation, things important to the person surrounding the self. The function of the self-shield is most often to "protect" one from the disease, but here this function cannot be asserted, since Maria depicts the disease, endometriosis, in the form of a uterus and ovary, as a "self".

It is important to point out that Maria separates herself from her surroundings with several intersecting, thicker lines, marking some extra protection, extra detachment from her surroundings. The husband, two girlfriends, Maria's mother and father, and two pet dogs are depicted close together as part of the "self-shield". All this is concentrated in a small size in the lower right corner of the page, the page is almost empty, there are job, doctors, and doing sport in the corners. Halfway between the doctors and job, she placed the IVF in a rectangle, expressing that the it was somehow separated, as she said, "it doesn't fit in the picture."

After talking about the drawing, Mara herself initiated that she wanted to "redraw" to show what her ideal layout would be, which would reveal the desired situation. In this second drawing, the self is only a circle surrounded by an outline, the disease is further away in the form of a circle, and the self is not affected by anyone, nothing. Relevant people were given more, breezier space to "move more easily if I wanted to," Maria explained. The test-tube got closer and got a circle shape, the doctors got a smaller circle next to the tube. Job and sport circles remained unchanged. Overall, the image shows a much busier, fuller, more harmonious layout. I asked her what was needed to have it realized, and Maria herself provided solutions: talk more openly with her parents, trust her partner more, be more accepting of the test-tube and the doctors. I gave positive feedback on this action plan, as she formulated her own goals and opportunities for the near future, which increased her motivation, commitment and sense of control.

2.5. The Closure of the Case

Maria's relationship towards herself also changed a lot. As she was able to open up more and more to his partner and firmly trust her doctor who looked at her as a partner, as well as our relationship, she began to become more and more tolerant and accepting her own self. At the end of the last meeting she said that she did not think she should be blamed for her illness, which is the reason of her fertility problems. She sees her own body as a partner who will help her to become a mother, a partner in achieving this goal, and she will be happy to receive the medical help she needs towards that goal.

The client gave a high score on guilt questions in the first interview on the Beck Depression Questionnaire (Beck et al., 1961) (I constantly blame myself. I deserved the punishment.). These feelings were dissolved at the end of the work. The original score (14 points, moderately severe) improved significantly compared to the condition recorded in the first interview (6 points, the lower limit of the mild state) by the end of the process.

An important result is that by the end of working together, the couple will no longer see their marriage as shattered by the difficulties of having children, and they can even imagine that they will get even closer together and deepen their relationship by overcoming the obstacles together. This shows the potential for post-traumatic development.

Maria was able to overcome her negative experiences and put her confidence into a team to help her. At our closing consultation, she said goodbye to me: "As much as I was afraid of IVF, now I find myself looking forward to it… I'm open to good things finally happening to us."

3. Conclusion

Based on the reviewed research findings and the case study described, it is clear that the treatment of endometriosis necessitated an integrated approach that recognizes the role of psychological factors. In this, adequate knowledge of the psychological aspects of treatment can be expected from all members of the healthcare professional. Extra attention should be paid to make sure that women do not feel marginalized and see their concerns belittled. They need medical staff to acknowledge the reality of their concerns, and both reassurance and information play a major role in this (Slade & Cordle, 2005) In the title of his study, Lachowsky (2012) goes as far as to ask the question: who should treat a patient with endometriosis: a gynecologist, a doctor, or a psychologist? Physical and psychic pains – even if they don't add up – are mutually reinforcing, especially when the past is overshadowed by other difficult life events. For many years, women with endometriosis have found themselves branded neurotic, hysterical, not treated as "real" patients, denying the reality and significance of their now-recognized pain. A breach of human dignity can be healed if medical staff recognizes and acknowledges the difficulties associated with the condition, treating patients in a

multidisciplinary approach. While writing this chapter and practicing my profession, one of my main goals has been to achieve the team work of professionals of different disciplines to work as a team for the health, present, and future well-being of patients.

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