

Models for Future Research

For research on vulvodynia to progress, definitions should be standardized for the terms that describe vulvodynia and the conditions that are associated with it. The terms and procedures used to characterize the pain associated with vulvodynia should also be standardized. Many biologic mechanisms are currently being investigated, including inflammatory and infectious disease processes, stress factors, neurologic and genetic factors, and the relationships between these processes and hormonal and immune system changes. Establishing the natural progression of vulvodynia will contribute toward a better understanding of the role of etiologic factors (causes).

Methodological and Other Issues To Be Resolved

The NIH will continue to foster and support research focusing on basic, clinical, translational, and/or behavioral studies that expand our knowledge of vulvodynia, and to coordinate educational efforts for patients and physicians based on research and scientific evidence. To further outreach efforts, the NIH is working with the National Vulvodynia Association, the American College of Obstetricians and Gynecologists, and other professional organizations to explore the development of a national educational program for primary health care providers, patients, and the general public regarding vulvodynia's symptoms, diagnosis, and treatment options. The NICHD, the National Institute of Neurological Disorders and Stroke, the NIH Pain Consortium, and other agencies in the U.S. Department of Health and Human Services are collaborating with the ORWH on these efforts aimed at advancing research and education on vulvodynia.

REFERENCES

1 Harlow BL, Stewart EG. A population-based assessment of chronic unexplained vulvar pain: have we underestimated the prevalence of vulvodynia? *J Am Med Womens Assoc.* 2003;58:82-88.

2,3 Bachmann GA, Rosen R, Pinn VW, et al. Vulvodynia: a state-of-the-art consensus on definitions, diagnosis and management. *J Reprod Med.* 2006;51(6):447-56.

Frequently Asked Questions (FAQs) about Vulvodynia

What is vulvodynia?

Vulvodynia is chronic unexplained pain or discomfort of the vulva. The vulva is the area of the female genitals surrounding the vaginal opening and includes the labia, the vestibule, and the perineum. Some women refer to it as “the pain down there” or as “feminine pain”. It affects all women, including racial and ethnic minorities, women with disabilities, sexual minorities, and those in rural and urban areas.

What are the symptoms of vulvodynia?

Women with vulvodynia often experience burning, stinging, irritation, rawness or stabbing pain in their genitals, with no apparent explanation. The pain or discomfort can be chronic or intermittent, and generalized or localized to one area of the vulva. Some women also report itching. For many women, sexual intercourse, and even tampon insertion or wearing clothes (such as underwear or trousers) is very uncomfortable or painful.

What causes vulvodynia?

Do I have an infection or disease?

While a number of causes have been proposed, researchers still don't know why vulvodynia happens to some women. Most likely, there is no single cause. Because of this, vulvodynia remains difficult to assess and diagnose. Many health care providers are not aware of the existence of vulvodynia, so aren't always able to diagnose it. As a result, many women may go for a long period of time without diagnosis.

How is vulvodynia diagnosed?

You should share with your health care provider information about your symptoms and related problems you are experiencing. In turn, your health care provider should talk to you about these symptoms and raise questions about your lifestyle, medications you may be taking, and your sexual and family history, in order to better understand the possible causes of your pain. Your health care provider should also do an examination of your pelvic area, including your vulva and vagina and laboratory tests to rule out other causes of your pain and discomfort. These causes could include endometriosis, a yeast infection, a sexually transmitted infection, or dermatitis. The diagnosis of vulvodynia can be established after ruling out other causes of your pain and discomfort.

Is there a treatment or cure for vulvodynia?

While there is no cure, there are a number of treatment options for vulvodynia. These can include advice on general vulvar care, topical and/or oral medications, physical therapy exercises, injections, biofeedback, or even surgery in some specific cases. Although no single treatment is effective for all cases, a multi-faceted approach to prevent and reduce symptoms can improve quality of life. You and your health care provider should work together to develop a strategy of treatment that works best for you. Many women find that wearing only cotton underwear, not wearing panty hose, or tight-fitting jeans or other clothes around their pelvic area, using only white, unbleached toilet tissue and 100% cotton sanitary products (tampons and pads), and washing their genitals frequently with water and avoiding using creams, soaps, douches, or deodorants on your vulva also helps. What is important is to find a low stress strategy for you that reduces the pain and discomfort.

How may vulvodynia affect my personal relationships?

For many women, vulvodynia may result in sexual activity being very uncomfortable and even painful. Because of this, vulvodynia may also cause emotional stress for women whose intimate partner may not fully understand the effects of this condition. Women should be encouraged to discuss vulvodynia openly and honestly with their partner and should not feel obligated to engage in sexual activity if it is painful. More information on this issue is available from our partners, including the American College of Nurse-Midwives (www.acnm.org), the American College of Obstetricians and Gynecologists (www.acog.org), the International Society for the Study of Vulvovaginal Disease (www.issvd.org), and the National Vulvodynia Association (www.nva.org).

Did my partner give this to me? Can I give this to my partner?

There does not appear to be a link between sexually transmitted infections and vulvodynia; thus it cannot be shared among sexual partners. However, because vulvodynia can interfere with a woman's enjoyment of sexual activity, women should

discuss vulvodynia openly and honestly with their partner.

Is there something a woman can do to prevent it?

This is still unknown. Further research is needed to assess the causes and underlying factors that contribute to vulvodynia.

How do I talk to my health care provider about vulvodynia? For many women, talking about pain or discomfort that occurs in or around their genitals can be very uncomfortable and difficult. Women may feel embarrassed, or worry that they might have a sexually transmitted infection. Others may worry that their health care provider won't take them seriously and dismiss their concerns as unimportant. Some may have raised this with other providers, and felt frustrated by their responses. Nevertheless, it is very important that women tell their health care providers about any pain and discomfort they are experiencing, being specific about where the pain and discomfort occurs, when it started, and whether or not the pain and discomfort is episodic in nature. Be open about what sort of home remedies you may have tried, and whether or not there have been other changes in your medical history. While you may indeed have vulvodynia, it is entirely possible that there may be another cause for your pain and discomfort, and you and your health care provider will want to determine that as well. If your health care provider does not respond to your concerns you should raise the possibility of vulvodynia with them, or seek another opinion.

Why did it take so long for my health care provider to diagnose it?

Many health care providers are unaware that vulvodynia is a diagnosis. Further, most health care providers will want to make sure that your vulvar pain doesn't have another organic cause.

How many other women have vulvodynia?

Because many women are reluctant to report symptoms of vulvodynia to their health care providers, and because many health care providers don't always quickly diagnose vulvodynia, assessing how many women have vulvodynia is difficult. Nevertheless, researchers conservatively estimate that over their lifetime, as many as

18% of women will experience symptoms consistent with vulvodynia. Symptom onset appears to be highest among women between the ages of 18 and 25, and lowest for women older than 35. As noted before, vulvodynia knows no ethnic or socio-economic boundaries, and affects all women, including women with disabilities, sexual minorities, and rural and urban women. Once considered a condition that affects primarily Caucasian women, several recent studies have shown that African American and Hispanic women are equally likely to develop vulvodynia. More studies are needed to understand the risk factors, etiology, diagnosis, and clinical management of vulvodynia.

What research is being done about vulvodynia?

Researchers continue to explore better clinical definitions of vulvodynia, better methods of identifying conditions that co-exist with vulvodynia, the etiology of the condition, risk factors associated with its development and more comprehensive clinical management tools for vulvodynia. NIH encourages investigators to submit qualified applications for further studies on vulvodynia to appropriate program announcements.

Where can I go for more information about vulvodynia?

The website of the Office of Research on Women's Health, the National Institutes of Health, U.S. Department of Health and Human Services (<http://orwh.od.nih.gov/health/vulvodynia.html>) has additional information on electronic and print resources regarding vulvodynia.

Other resources are also listed in this brochure.

