Women's Sexual Health Journal

Editorial

One of the joys of being the editor of a journal is the opportunity to review and assemble a variety of material into a cogent piece of work. Sometimes my cup is overflowing. This issue we have a poignant story of a woman whose decision to have an abortion when she was young affected her sexuality. My dear friend and colleague, Jean Fourcroy, has provided an article on the effect of culture on women's sexual health, focusing in particular on the practice of female genital cutting. This practice is much more widespread than I realized.

Michael Goodman, a gynecologist, has written a very helpful guide for patients facing a hysterectomy or uterine artery embolization. He advises women to prepare before a procedure by asking questions and educating themselves about the ramifications of each procedure.

Ros Washington, a volunteer with the Foundation, attended a meeting in Washington DC addressing federal funding of research on pelvic pain in women. The presentations at that meeting suggest that the future is improving for recognition of the importance and prevalence of women's sexual health issues and that there are members of the legislature willing to support bills increasing funding of related research.

Our sexual medicine article this issue is ***Circulating Androgen Levels and Self-reported Sexual Function in Women*** by Susan Davis et al. This is an important paper for two reasons. First , it muddies the waters of FSD research. Second, the media and clinicians have jumped on this paper as vindication for "anti-medicalization" factions. I will discuss this paper later in this editorial.

TWSHF welcomes three distinguished clinicians to its Advisory Board: Jean Koehler, PhD, Eusebio Rubio, MD, PhD, and Ridwan Shabsigh, MD. Advisory board member Talli Rosenbaum has had two papers published in the Journal of Sex and Marital Therapy. Columbia University and TWSHF sponsored a very successful meeting at Columbia in April providing a multidisciplinary update on FSD. As a result of many requests we will be conducting another meeting next year in April.

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One of the other joys of being an editor is that I get to ramble on whatever suits my fancy. I have been bothered for some time about the fighting that goes on within the sexual health community, particularly in the United States. There is a faction of sex therapists supported by a free lance journalist that sees conspiracy behind every tree. They claim the pharmaceutical industry is inventing diseases for the obvious profit motive. They decry the "medicalization" of sexual problems. They object to words like "dysfunction" and "disorder." On the other side, there are medical physicians who attempt to deal with all sexual problems with drugs, surgery, and other medical procedures but fail to recognize or only give lip service to the psychological factors. It is about time that this fighting stop. Grow up!

Patients will be best served by truly using a multidisciplinary approach. A sexual problem/ disorder/dysfunction may have both medical and psychological etiologies. Certainly such problems will have psychological impact on the patient and her

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Articles, letters, and questions may be submitted to the Editor, David Ferguson, at info@twshf.org.

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partner. Arguments over the political correctness of words serve nobody. Each discipline should recognize the limits of its ability and embrace the opportunity to coordinate diagnosis and treatment plans with other disciplines. Talk cannot mend a broken leg, nor can drugs mend a broken heart!

At times, I suspect that the true motivation behind the behavior of these two factions is economic — that these providers fear losing patients to another provider. Similar events occurred in the field of male erectile dysfunction (MED) as pharmacologic treatments became available. Prior to that time, MED (impotence) pretty much belonged to the therapists. It was estimated that 90% of MED was psychogenic in origin. Today, it is estimated that there is an organic component to MED in 90% of sufferers. What a turnaround!

Until recently, the majority of physicians presented with a patient complaining of a sexual problem would tend to dismiss it as "all in your head" or refer the patient to a therapist. Now, we advocate both therapists and physicians thoroughly explore medical causes of sexual complaints. Are these complaints a side effect of medication, e.g., antidepressants or oral contraceptives? Is there an underlying disease that impacts sexual function, e.g., diabetes? Are hormone imbalances contributory, e.g., thyroid, glucocorticosteroids, androgens, estrogens? No amount of talk therapy will be truly successful if underlying physical problems are not addressed. Advocates of a mind-body approach to sexual health recognize the constant interplay and complexity of the physical and the psychological. Neither operates in a vacuum. Similarly, no patient will realize her true sexual health potential if only her physical problems are addressed. We all need to work together for the patients.

This Journal issue's sexual medicine article by Susan Davis et al adds fuel to the fire in this ongoing bickering. The "antimedicalization" faction has embraced this article as proof that testosterone is unimportant to women; that it is just another profit-motivated ploy by the pharmaceutical companies to victimize women. I don't think the article supports that. In fact, the authors say, "Our results are not in conflict with testosterone being used pharmacologically to treat hypoactive sexual desire disorder…" I am not the best person to provide a complete critique of this article, but I see danger in the conclusions of the authors. They say, "The measurement of serum testosterone, free testosterone, or DHEA-S in individuals presenting with low sexual function is not informative and levels of these hormones should not be used for the purpose of diagnosing androgen insufficiency in women."

The danger in this conclusion is that it may lead physicians to NOT measure hormones when working up a sexual dysfunction patient. Combined with Davis et al's other conclusion, physicians may initiate testosterone treatment inappropriately. I know of a woman who presented with many of the symptoms of female androgen insufficiency and was begun on testosterone treatment without any hormone testing. She quickly developed side effects and had the testosterone discontinued. After a suitable recovery period, her hormones were measured. It turned out that her baseline testosterone was in the high normal range for women. This little medical misadventure could have been avoided if the attending physician had ordered hormone tests prior to instituting treatment.

I expect that the true role of androgens in women will take years to elucidate. If it turns out that there is a place for testosterone therapy, I suspect therapists will find their job easier when underlying hormonal imbalances have been addressed. Physicians should carefully consider baselines before attempting a therapeutic trial of any drug. All providers in the sexual health community should work together for the benefit of patients. It is about time! *Editor—David Ferguson, Grand Marais, MN*

A Woman's Story: Loss of Innocence

I remember the "first time." I was deeply in love and glad I waited till I was 21 and finally in the arms of the perfect man. He was my hero, a helicopter pilot in Viet Nam, whom I met through correspondence, never imagining that he had grown up only six blocks away from me. He was "the cutest thing going" and I made him "the happiest man east of the Mississippi."

I recall the ecstasy of our first sexual encounter; our romantic trip to Puerto Rico together to share in our roots. And the disappointment that I felt when I told him that I was pregnant. It wasn't his response, but the lack of it that worried me.

I had grown up in a very close-knit, Catholic family and was aware that my pregnancy would make me an outcast in my family's eyes. It was the early 70's and unwed mothers were looked down upon, rather than admired for their courage, as they should be today. Abortions had just become legal in New York State, and it seemed the only alternative.

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How I wish I had been brave, but at the time, it seemed to be the best decision I could make. I didn't want to burden my boyfriend, who was dealing with so many post-war issues, with the additional charge of supporting a child. The understanding counselor at Planned Parenthood agreed with me that "the timing was not right" and that, with luck, I would go on to have other children.

Five minutes before my scheduled appointment, he balked and asked me to marry him. Somehow, it didn't seem like the right reason to want to marry me: because I was pregnant. I wanted him to say that he loved me and didn't want me to go through with it. But he didn't and I went ahead reluctantly with my original plans.

I thought that I would be "okay" with my choice, that it was a simple procedure, an easy way out of a bad situation, but it wasn't. It was a terrifying and excruciating painful ordeal. Nor was I prepared to deal with the loss of a child. For years, I could not see a mother with her child without feeling an extreme loss. Even now, so many decades later, I often stop to wonder how old my first child would have been, what he or she would have looked like, the grandchildren that I've missed.

I was fortunate, in that my boyfriend eventually did marry me and we did go on to have a child. But if that hadn't happened, I know that I would still be very bitter. And in a way, I am. I never again felt the pleasure of sex that I felt "the first time." Perhaps the feeling was associated with too much pain. Perhaps I am afraid to ever be as vulnerable again. But I have never had the pleasure of an orgasm while having sex since.

I never even considered it unusual, until I began reading the brochures published by The Women's Sexual Health Foundation. I only realize now that I have missed out on an important aspect of my life. And I have since remarried. I can't imagine how my lack of sexual response has impacted our marriage.

In the next few weeks, I hope to have the courage to talk to my doctor about it and perhaps begin my journey back to the hopeful, trusting girl I once was. A*nonymous*

Do Customs and Culture Play a Role in a Woman's Sexuality?

A woman's sexuality must be considered in the context of the environment in which she lives. Culture, social customs of the community, as well as religion often determine in large part the acceptance and achievement of sexual health for both men and women. Tradition determines, and may dictate, a woman's freedom to achieve and enjoy sexual health throughout her entire life span – from puberty, marriage, pregnancy, and even menopause and old age. Her tribe, her religion, and/or her matrilineal line often determine what she can or cannot do as well as what pleasure she can enjoy. Tradition, law, education, and the status of women are important indicators of sexual health often not considered in studies evaluating sexual attitudes or behaviors.

Sexual Health is an assumed right for every individual, both male and female; this right requires a positive and respectful approach to sexual relationships, and allows her pleasurable and safe sexual experiences. Coercion, discrimination, infidelity, and/or violence in any culture is detrimental to a woman's sexual health. We know that discrimination and violence are a part of the lives of many women world-wide. Education of women may be the most important socio-economic piece of the puzzle to preserve the sexual health of women.

Table 1

Sexual health assumes that each individual:

- Receives the highest attainable standard of health in relation to sexuality, including access to sexual and reproductive health care services;
- Be able to seek, receive and impart information in relation to sexuality;
- Have sexuality education;
- Have respect for bodily integrity;
- Have a choice of partner;
- Be able to decide whether to be sexually active or not;
- Be able to have consensual sexual relations and/or marriage;
- Be able to decide whether or not, and when to have children; and
- Be able to pursue a satisfying, safe and pleasurable sexual life.

Little is known about the role of culture and tradition and how it impacts a woman's sexuality. Studies repeatedly show that sexual difficulties are common among mature adults around the world – but these studies almost always exclude populations with unique cultural inheritance. They exclude immigrant and minority populations when evaluating the incidence or prevalence of such problems as arousal,

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lubrication, and orgasm. No studies have truly tried to capture a woman's viewpoint in developing countries. Additionally, many studies use endpoints that may not reflect a woman's sexual satisfaction, e.g. frequency of coitus tells little about a woman's initiation or participation in these sexual events. It is difficult to capture the effect on a women's sexual health in countries and areas where we are an outsider. I would suggest we might learn from one example – what is the effect of female genital cutting (**FGC**) on a woman's sexuality?

What is FGC? The origin of female cutting rituals cannot be traced but appears to have been practiced as early as the time of the Egyptian Pharaohs. It is not an Islamic practice, and there does not appear to be a religious connection. The "circumcision" of girls, in any form, predated Islam by many centuries. This 'ritual' was probably practiced in some parts of Arabia at the time of the Prophet Muhammad but does not appear to have been a practice of all. FGC is practiced by both Muslims and non-Muslims alike residing in sub-Saharan African in countries that include, but are not limited to Egypt, Sudan, Somalia, Ethiopia, Kenya and Chad. The procedure varies in practice within a country's tribes. A more minor form of the procedure is also performed in some parts of the Middle East and south Asia. In Africa and the Middle East it is performed by Muslims, Coptic Christians, members of various indigenous groups, Protestants, and Catholics. The procedure is also found among some ethnic groups in Oman, the United Arab Emirates, and Yemen, as well as in parts of India, Indonesia, and Malaysia. It is not a religious custom.

Immigration patterns from countries where the tradition is practiced remind us of the importance of understanding the impact of this procedure in the United States. Estimates of the prevalence in the United States have been made based on prevalence of these families throughout the country. It was estimated in 1990, that nearly 168,000 immigrant women and girls in the United States had either undergone FGC or were at risk for this practice. In many ways, FGC is a custom controlling a woman's body; it is thought to preserve a family's honor and prevent promiscuity and immorality. It is claimed that the custom is perpetuated because a circumcised woman provides more sexual pleasure for her husband while ensuring cleanliness and chastity. It is thought to minimize the sexual appetite of a woman thus reducing the likelihood that she will bring shame on the family through sexual interactions. Her purity ensures her attractiveness to potential suitors. It is a mark of cultural identity.

The sexual complications of FGC have not been well researched, and there are conflicting reports. The removal of a woman's external sexual organs (such as the clitoris), and infibulation (removal of part or all of the labia) may leave the woman with little sexually sensitive genital tissue. Although the cutting does not affect the hormones that contribute to sexual arousal, the missing structures and tissue can have a negative effect on sexual desire, arousal, pleasure, and satisfaction. Other sexually sensitive parts of the body, such as the breasts, nipples, lips, neck, and earlobes, may become increasingly sensitive in women who have undergone FGC to make up for the lack of clitoral stimulation. Type and depth of the genital cut also impact on sexual responsiveness.

There are discrepancies in reports of the effect of FGC on a woman's sexuality. The extent of the cutting – from part of the clitoris to everything in sight – may reflect some of the differences. Some researchers report no change, while others note statements such as "when I make love with my husband, I can't handle it. I don't want to see him because I have a lot of pain." Lightfoot-Klein reported that close to 90% of Sudanese women she interviewed claimed to achieve, or had at some time in their lives achieved, orgasm. Gruenbaum concluded that "the effect of female circumcision on sexuality is not uniform or sufficiently well understood." It would appear that the various forms of female circumcisions are not equally devastating to female sexuality. Orgasmic response may vary according to the amount of clitoral tissue removed, variation in erogenous stimulation, as well as a woman's expectations. However, there can be no doubt that many of the circumcision practices can alter physical well-being, including sexual responses. The psychological aspects of a painful procedure in a young child may forever impact her sexual responsiveness. The trauma of circumcision may always influence a woman's sexual life.

Measures of female sexual function often use coital frequency as a surrogate marker of normal sexual function. Unfortunately, there is no way to identify in many studies who initiated the sexual act. In one study, women whose clitoris was not cut were significantly more likely to report that the clitoris is the most sexually sensitive part of their body, while women who were cut were more likely to report that their breasts were the most sexually sensitive body parts. Cut women were significantly more likely than uncut women to report having lower abdominal pain and vaginal discharge. Female genital cutting in this group of women did not attenuate sexual feelings.
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However, other customs in these societies may predispose women to adverse sexuality outcomes including early pregnancy and reproductive tract infections. Depression and other psychological disorders may be important and innocent sequalae of the cutting – this has not been studied.

Do male expectations determine the prevalence of and the sexual response of the woman? An important aspect of assumed male sexual pleasure is the culturally defined anatomic appearance. Male preference is for smoothness of the vulva in cultures practicing female circumcision; a husband may find a woman's body distasteful if her vulva is not smooth. A woman's sexual pleasure may be determined by the cultural norm set by the male. Does the presence of the male's multiple partners outside the home play a role in a woman's sexual response? Infidelity and multiple partners may be the norm in some areas.

In many of these same cultures practicing FGC, a dry vagina is also deemed important – although the dryness is not well defined. The role of agents thought to dry and tighten a woman's vagina and serve as love potions to attract sexual partners and ensure their faithfulness is unclear. It is presumed that these agents draw out moisture, but such astringent agents may be important to reduce secretions from the high prevalence of vaginal infections in these areas.

Can we learn lessons from the practices in one culture? Although the role of FGC in the normal cycle of sexuality is unclear, I believe there are some similarities to other western cultures. FGC controls a woman. FGC is supposed to control sexuality before marriage – although in many of these areas, it is important for her to prove fertility before marriage. Sexual pain disorders may play a role in desire, arousal, and orgasmic sexual responses. In all cultures, sexual dysfunction is highly associated with negative experiences in sexual relationships and overall well-being. In interviews by Dr. Tobia with genitally cut women, it was found they had experienced orgasm at some time. Their statements were "qualified by the fact that they were not always sexually satisfied, and it was the nature of the relationship and the sensitivity of the partner that made the difference." Many couples can have a fulfilling relationship because of the deep emotional bond, camaraderie, and social compatibility even if the sexual aspect is missing. The woman is not being controlled. The nature and strength of the relationships may be the most important factor across all cultures. I suspect we know little about the effect of a woman's family, religion, and education on her sexual health in any culture.

Table 2

In summary, the proponents of FGC believe that:

- The ritual reinforces a woman's place in her given society.
- The ritual establishes eligibility for marriage.
- The ritual initiates a girl into womanhood.
- Female genitals are unhygienic and in need of cleaning.
- Female genitals are ugly and will grow unwieldy if not cut back.
- The ritual safeguards virginity.
- The ritual prevents maternal and infant mortality.
- The ritual improves fertility.
- The ritual enhances a husband's sexual pleasure.

World-wide, the control of a woman to meet cultural and religious expectations will control her pleasure. Education for women and their daughters will be key to improving a woman's sexuality. I believe that customs and culture play a very important role in a woman's sexuality – a role we have yet to understand fully.

Jean L. Fourcroy, MD, PhD, MPH

Dr. Fourcroy received her M.D. from the Medical College of Pennsylvania and her Ph.D from the University of California at San Francisco with board certification in Urology in 1981. Currently, she is a consultant in regulatory issues in the development of drugs and devices after retiring from FDA. Dr. Fourcroy has long been involved in the scientific issues related to women's health, particularly sexual function.

Questions and Answers

Q: I am a woman with diabetes. It seems like my sex life has changed over time since I have had diabetes. How can this disease impact sexual health?

A: There are women with diabetes who will not

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notice a change in sexuality. However, others may notice vaginal dryness, yeast infections, and sometimes UTI or urinary tract infections. These problems can make one unenthusiastic about having sex, and sometimes women will even start to avoid sex.

To prevent a UTI, urinate before, and as soon as possible, after having sex. This can help to decrease the chance of getting a UTI. Vaginal lubricants can help with dryness and speak with your healthcare provider about the appropriate treatments for yeast infections.

Also, diabetic women may experience decreased sensation in the genital area. This may be due to nerve damage from the diabetes. In this case, a woman may need extra stimulation, and a vibrator may be very helpful.

Q: I have hypertension, and my doctor said that there was no way that my high blood pressure could be causing dryness and a problem with orgasms. I never had a problem before my high blood pressure. Is my doctor correct?

A: Some women with high blood pressure complain of vaginal dryness and trouble reaching an orgasm. So you are not alone. Also, various high blood pressure medications can impact sexual function. Speak with your healthcare provider about your concerns, and ask her if switching medications could be helpful in your case. You should also consider a vaginal lubricant such as Astroglide or Replens.

Q: My husband is not in the mood for sex anymore. I am in my forties and so is he. I really enjoy sex. What should I do?

A: First, have a heart-to-heart talk with your husband about your concerns. Aging may bring on a loss of desire and so may stress, lack of sleep, and even performance anxiety. Medications and various medical problems can impact a man's sexual function and desire. He should also have a complete physical and talk with his healthcare provider about his lack of desire.

Preparing for Hysterectomy and Uterine Artery Embolization

Hysterectomy ("hyst.") is one of the most common operations undergone by women. Uterine Artery Embolization ("UAE") is finding increasing popularity as an alternative to hysterectomy for therapy of benign tumors of the uterus and abnormal uterine bleeding in women who, for a variety of reasons, wish to retain their uterus.

Leaping past the issue of whether either procedure is necessary for you (that could generate a whole separate article!), women are frequently ill-prepared for the consequences of their procedure. Surgical gynecologists and interventive radiologists are not necessarily in the habit of performing extensive workups or making time available for counseling on the potential sexual fallout from either procedure. "You're bleeding...well, cut it out" (or occlude the blood vessel) and, if your ovaries have been removed, "give you estrogens..." One visit. Case closed.

Well...there is a lot more to it than that. What follows will be in two parts: What to ask (and demand) from your doctor (gynecologist or radiologist) prior to surgery and, what to expect and how to deal with it.

WHAT TO ASK

1. "What is my problem as you see it?" [Is this really <u>your</u> problem as <u>you</u> see it?]
2. "Why do you feel I need a hyst (or UAE); what will it accomplish? [Is this what you wish to accomplish?]
3. "What are other avenues -- surgical, radiological, nonsurgical, hormonal, etc., for accomplishing what I wish? What are the pros and cons of each?" [Do any of these alternatives seem to warrant further exploration?]
4. How long will I be in the hospital or outpatient facility? What about pain? When can I return to general activities? Sex? Work? What are the risks?" [Is this acceptable to you?]
5. "With this procedure, will I require hormonal therapy afterward? If yes: What do you have in mind?" [Make sure that you fully understand this before the procedure. If ovaries are to be removed, make sure, in addition to estrogen, that testosterone is provided].
6. "In what ways might this procedure effect me sexually?"
7. If you are having a UAE, be sure to make your radiologist aware that you expect him to be careful and <u>selective</u>, occluding the uterine arteries distal to ("after") the blood

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vessels that supply other parts of the pelvis exit from the uterine artery.

Schedule an appointment solely for the purpose of discussing these matters. If your interventive radiologist or gynecologist is not able, or doesn't adequately answer your questions -- find another practitioner!

WHAT TO EXPECT AND HOW TO DEAL WITH IT

With either UAE or hyst (whichever the approach: abdominal, vaginal, laparoscopic or supracervical) you are having a surgical procedure involving a very vulnerable area. Be prepared for this. Discuss it with yourself, your partner, your physician and your therapist if applicable. How do you feel about it? What about your ovaries? Will it be best to leave them in and let them function (or dysfunction) as the case may be? Or to remove them, substituting estrogen and testosterone and possibly progesterone--which could either be a hassle or immensely beneficial, depending on how those ovaries are presently functioning (more about this later).

1. Loss of your uterus (hysterectomy): Be prepared to experience this as a loss. A part of you--the organ where your children grew (or perhaps where you wanted them to grow if you are involuntarily childless) is being removed. On the other hand, if there is bleeding, pain, etc. -- this may be a huge relief.
2. Loss of ovaries: Same as above. If your ovaries are synonymous with your femininity--think it over seriously and discuss with a therapist or your gynecologist if the issue is unresolved. A good rule of thumb: If you are psychologically attached to your ovaries and they help define your femininity, leave them in! If, at any age, there are serious disturbances stemming from hormonal dysfunction (e.g. severe PMS, menstrual migraine, etc.) consider taking them out and going on hormone therapy. On average, your ovaries run out of eggs and hormones +/- age 45-55, so if you are over 45, you may consider removal and estrogen/testosterone which will usually guarantee a smooth transition and eliminate peri-menopausal/menopausal symptoms entirely (you won't go through menopausal changes, as you are already "transitioned" to hormone therapy). Later, after you are stabilized, you can work on a slow hormonal taper-down if you wish.
3. UAE: Why does a heart attack hurt? Because muscle is being deprived of blood and oxygen and is dying. The same with the uterine muscle in UAE. It can hurt like H for several days. Be prepared with pain meds and NSAIDs. Additionally, understand if the embolization is not as "selective" as hoped, you may have significantly diminished sensation in vaginal, vulvar and clitoral areas.
4. Sexual functioning: Not infrequently, for factors related to the reason you are having your procedure in the first place, you and your partner may have grown sexually distant. Then, for a period of time (4-6 weeks; significantly less with UAE and supracervical lap hyst), you won't be able to enjoy intercourse. Initially you will be fatigued; you will be hurting--both hyst and UAE are a little like getting run over by a truck. Discuss this with your partner. Openly acknowledge the situation if you have grown sexually distant. Do you and he wish to be closer? Discuss this. It is not at all unusual for midlife women and women with uterine maladies to have a significant diminution in desire for a variety of reasons (hormonal changes, poor sleep quality and fatigue, pain, bleeding, etc.). Get your hormones balanced with estrogen and testosterone replacement if your ovaries have been removed, and possibly the same (perhaps even adding progesterone) if you still have ovaries but are perimenopausal. This and the resolution of the medical problem will help, but don't necessarily expect the desire to come all back. It frequently doesn't. You can still work your way back to enjoyable and fulfilling sexual relations.

SOME IDEAS

a) Even though you may not be able to have intercourse, you and your partner can still engage in single or mutual self-pleasuring, fantasy, oral sex, touching, kissing, etc.

b) SCHEDULE "DATES"! This really takes the pressure off both of you.

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Schedule "intimate time" at least once (hopefully twice a week) in bed, at a time when you can be private and when both of you are fresh. This is a time for intimacy, for sharing, for re-establishment. A time for communication, for new directions, for erotica and fantasy and perhaps arousal. And, who knows, "desire" may follow...

Remember: What determines post-procedure sexual functioning is pre-procedure functioning and preparation**.**

The more prepared you are, the more you have thought about it, and discussed it with your family, doctor, and counselor, the better you will do afterward. An excellent reference for women about to undergo UAE or hysterectomy is "A Gynecologist's Second Opinion" by William H. Parker, M.D. (Plume Books, 2003 edition).

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In The News: Chronic Pelvic Pain: The Pain Is Real!

On June 9, 2005, a luncheon briefing was held in Washington DC on Chronic Pelvic Pain: The Pain Is Real! Advocating for research funding concerning women's sexual health difficulties is one element of The Women's Sexual Health Foundation mission. Ros Washington attended this luncheon on behalf of The Women's Sexual Health Foundation.

The briefing was opened with introductory remarks by U.S. Representative Stephanie Tubbs Jones (D-OH). Representative Tubbs Jones will be introducing legislation to provide funding for research on uterine fibroids. Through research it is hoped the cause of fibroids will be discovered, including why African-American women have fibroids more than any other race. The funding would also be used to educate health care professionals and patients on fibroids.

Christin Veasley, Director of Research and Professional Programs with the National Vulvodynia Association shared her experiences as a woman with vulvar pain. Christin suffered for many years with severe vulvar pain. Her pain was regularly dismissed as psychological by the doctors she sought out to help her find a cause and remedy for her pain. It took Christin eight long years before she found a treatment.

Christin's vulvodynia had a huge impact on her marriage and family life. A great degree of embarrassment, mistreatment, and isolation are felt by sufferers of pelvic and genital pain. Research funding is severely lacking for pelvic and genital pain. Christin is very much a vocal advocate lobbying for funding to further research on the cause and treatment for this type of chronic pain.

Kathy Harrison spoke about being a sufferer of uterine fibroids, endometriosis, and vulvodynia. As with the case of Christin Veasley, Kathy was told she was exaggerating the pain, and it was all in her mind. She was told to cope with the pain – no one believed she could suffer that much pain. Several doctors labeled her as a hypochondriac. Kathy felt alone and isolated much of the time. Finally, a doctor was found after much searching that believed her pain was real and not imagined. The doctor took the time to diagnose her problems and began treatments. Her quality of life improved, and Kathy experienced much needed relief from pain until another problem presented itself. Her insurance would not cover her treatments. Kathy continues to battle the insurance company over coverage but must pay out of pocket for the treatments until such time as the insurance providers recognize pelvic and genital pain as legitimate health problems.

John Gibbons, Jr. MD, Past President of the American College of Obstetricians and Gynecologists presented on chronic pelvic pain, specifically how uterine fibroids, endometriosis, and vulvodynia impact pelvic pain. What causes fibroids, endometriosis, and vulvodynia is not well known. Uterine fibroids are benign tumors found in about 75% of women, and often without symptoms. However, African-American women have more clinical problems with fibroids. Symptoms can include pelvic pain, heavy periods, pain during intercourse, miscarriage, and infertility. Treatments can include medications, surgery, uterine artery embolization, and MRI focused ultrasound. Endometriosis affects 5.5 million women in the United States and Canada. Medications and surgery are the current treatments. Chronic vulvar pain is most often described as a burning pain, that can occur in the absence of relevant visible findings or a clinically identifiable neurological disorder.

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Unfortunately, gynecologists have limited expertise in the area of vulvar pain, and patients typically do their own research to find help and solutions. Furthermore, there are not sufficient data on the efficacy of treatments for vulvar pain such as vulvodynia.

The final presentation was by Linda Porter, PhD, Program Director in Systems and Cognitive Neuroscience at the National Institute of Neurological Disorders and Stroke at the National Institute of Health (NIH). She described the steps that the NIH is developing in pain research. There has been great collaboration between various institutes in this area, from the National Cancer Institute to the Office of Rare Diseases. Dr. Porter stated that one of the goals is to pursue a pain research agenda through public and private partnerships. There is a need to understand the pathophysiology of pain, and translate basic research into human pain management. One available resource is the pain consortium website at http://painconsortium.nih.gov/. The NIH currently has ongoing initiatives concerning vulvodynia, uterine fibroids, and chronic pelvic pain.

The briefing hit home. There is much to be done in the way of research on women's sexual health issues. Chronic pelvic pain is a serious and devastating problem affecting millions of women. Public awareness is needed. More importantly though, sophisticated federally funded research is desperately needed. In 2002, NIH spent $5.8 million dollars on uterine fibroids, but $17 million on urinary tract infections which impact fewer women than fibroids. Funding increased to $13 million in 2005. However, Representative Tubbs Jones and Senator Barbara Mikluski are planning on reintroducing The Uterine Fibroid Research and Education Act to provide more funding for research and education.

Ros Washington and Lisa Martinez

Sexual Medicine Article

Circulating Androgen Levels and Self-reported Sexual Function in Women, *Susan Davis, Sonia Davison, Susan Donath, and Robin Bell. JAMA, July 6, 2005;* ***294:*** *91-96.*

Female sexual dysfunction is prevalent in Western societies based on a number of epidemiology studies. Low desire appears to be the most common complaint. This has been associated with increasing age and also oophorectomy. Therapeutic trials with testosterone have demonstrated amelioration of this symptom. The Princeton Consensus group formulated the "female androgen insufficiency" syndrome characterized by a constellation of symptoms and a low free testosterone level. The authors of this paper sought evidence for a hypothesis that low sexual function in women can be identified by laboratory testing of androgens. I have summarized their paper below. Editor.

Methods

Women (18,021) aged 18 to 75 years were approached from Victoria, Australia using balanced randomized sampling based on voters' rolls. Women were excluded for a variety of reasons including antidepressant usage and oral contraceptive usage in those under age 45. A total of 1021 women remained after exclusions were applied.

Sexual health was assessed using the Profile of Female Sexual Function (PFSF), a validated self-report instrument that covers seven domains: desire, arousal, orgasm, pleasure, sexual concerns, responsiveness, and self image.

Serum total testosterone was measured by a radioimmunoassay method. Free testosterone was not measured but rather was calculated using the Sodergard equation. DHEA-sulfate and sex hormone binding globulin (SHBG) were measured using a chemiluminescent immunometric assay. Androstenedione was measured by a radioimmunoassay.

Power calculations at the 80% level indicated that a sample size of 1100 women would be needed. For some reason that was not adequately explained, the PFSF domain of "sexual concerns" was excluded from analysis. Again, the paper was unclear on how the subjects were defined as "low sexual function" versus "not low sexual function." Apparently, each domain had a possible score of 0 to 100, and the authors chose zero as the definition of low sexual function.

Rather complex statistical methods (Receiver Operating Characteristic (ROC) curves) were used to create contingency tables to determine odds ratios for assessing the usefulness of androgen levels at discriminating women with low sexual function from those without low sexual function.

Results

ROC analysis indicated total testosterone and calculated free testosterone were not useful for discriminating women with low sexual function for any of the analyzed PFSF domains regardless of age. DHEA-S showed a relationship for the domains of

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arousal, responsiveness, and pleasure for the older women (>45 years) and for desire, arousal, and responsiveness in the younger women. Androstenedione also showed a relationship to the pleasure domain in older women.

Comment

The authors discussed their results identifying strengths and weaknesses. Only 9.1% of the women identified eventually participated. The authors admitted the possibility of self-selection bias but then dismissed it. They proceeded to dismiss the utility of any of the androgens for diagnosis of female androgen insufficiency. "The measurement of serum testosterone, free testosterone, or DHEA-S in individuals presenting with low sexual function is not informative and levels of these hormones should not be used for the purpose of diagnosing androgen insufficiency in women." In contrast, the authors say, "Our results are not in conflict with testosterone being used pharmacologically to treat hypoactive sexual desire disorder…"

References: 29 (*Space restrictions prohibit listing them individually. Editor*)

Announcements

The Women's Sexual Health Foundation is pleased to announce the addition of three new members to its Advisory Board. Jean Koehler, Ph.D., past president of the American Association of Sex Educators, Counselors and Therapists (AASECT) will be joining the Board in the fall. She is well known for her multidisciplinary approach to dealing with sexuality. Eusebio Rubio-Aurioles, MD, PhD is an internationally known physician/scientist who has been instrumental in organizing Latin-American sexology and has served in a variety of leadership roles in many world sexual health meetings and organizations. Ridwan Shabsigh, MD is a urologist who has been intimately involved in male and female sexual physiology and pharmacology research. He is the Director of The New York Center for Human Sexuality at Columbia University, one of the first clinics to truly apply a multidisciplinary approach to helping patients with sexual health problems.

Welcome to these outstanding additions to our Advisory Board!

With the generous assistance of Dr. Eusebio Rubio, several of the brochures at www.twshf.org have been translated to Spanish. We hope to complete those and also add several other languages in the near future. Any of you who have multilingual skills particularly in medical translations will be welcomed as volunteers for this worthy effort.

Advisory Board Publications

Rosenbaum, T.Y. (2005). Physiotherapy treatment of sexual pain disorders *Journal of Sex and Marital Therapy* 31(4):329-340.

Ribner, D, Rosenbaum, TY (2005) Treatment of Unconsummated Marriage in the Orthodox Jewish Population *Journal of Sex and Marital Therapy* 31 (4):341-347.

Resources

Vulvadynia:

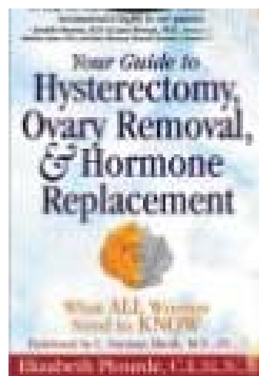
Vulvar Health
www.vulvarhealth.org

National Vulvodynia Association
www.nva.org

Uterine Fibroids:

The National Uterine Fibroids Foundation
www.nuff.org

Hysterectomy:



Hysterectomy & Ovary Removal: What ALL Women Need to KNOW
Plourde, Elizabeth. 2002.
Irvine: New Voice.

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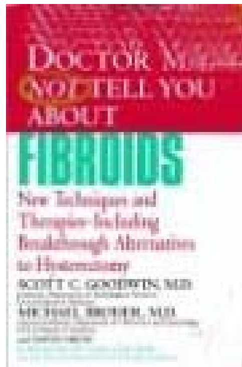

What Your Doctor May Not Tell You About Fibroids: New Techniques and Therapies--Including Breakthrough Alternatives to Hysterectomy Goodwin, Scott C, MD & Broder, Michael, MD. 2003. New York: Warner Books

A Gynecologist's Second Opinion Parker, William, & Rachel Parker. 2003. New York: Plume Books.

Meetings

Columbia University College of Physicians & Surgeons, Department of Urology *and* The Women's Sexual Health Foundation *PRESENT:* **Female Sexual Dysfunction 2006, A Multidisciplinary Update,** Saturday, April 22, 2006 *at* Columbia University Medical Center, New York, New York.

International Society for the Study of Women's Sexual Health, **2005 Annual Meeting**, October 27-30, 2005, Las Vegas, Nevada.

Donations

As a nonprofit organization, The Women's Sexual Health Foundation is supported through individual donations, memberships, and in a small measure, by the bulk sales of TWSHF brochures and the Journal. We are currently seeking to finance research projects through grants from government agencies and non-federal sources such as corporations, women's groups, and medical organizations. However, private gifts will always be the mainstay of the Foundation.

All donations are tax deductible. The Women's Sexual Health Foundation will send you an acknowledgement receipt for your tax records.

If you would like to make a donation, please send your contribution to:

TWSHF
PO Box 40603
Cincinnati, Ohio 45240-0603

Information

See www.twshf.org for information on membership, donations, instructions for authors, volunteering, and additional resources.

Editor's Note

The October 2005 issue of the Journal is in preparation. The Editor welcomes articles, letters, meeting notices, pertinent internet websites, breaking news, information on support groups, and publications that may be of interest to the readers.

We are all inundated with news articles about drugs, vitamins, and health. Many of these stories are written by journalists or TV reporters trying to sensationalize articles published in medical journals. Frequently, the reported results or conclusions do not stand up to scrutiny. Retractions and corrections usually get no attention from the media. I am appalled by the number of my scientific colleagues who do not have a clear understanding of basic statistics. The public too are deficient in this knowledge. Yet, everyday we are confronted with statistics and "medical studies." It is essential that all of us have the means to properly assess these reports. Therefore, I will prepare a brief course in statistics to be published in future issues of the Journal. Any of you who would like to contribute examples of articles that misrepresent the facts, or would like to direct the scope of my course, please e-mail me at ferguson@boreal.org. *David Ferguson, Editor.*

Disclaimer

TWSHF recommends that you consult with your health care provider to determine appropriate treatment. TWSHF is not responsible for any consequences that occur based on information contained in this publication.