Female Sexual Pain Disorders

Evaluation and Management

Edited by Andrew T. Goldstein, Caroline F. Pukall, Irwin Goldstein

Foreword by Yitzchak M. Binik



Female Sexual Pain Disorders

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FOREWORD

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We dedicate this book to those people who are most important in our lives: our patients, past, present, and future, who have and continue to suffer from sexual pain; our mentors, Stanley Marinoff, Irv Binik, and Robert J. Krane, who both taught and inspired us to follow in their paths and continue on our own; and most especially our families; our spouses Gail Goldstein, Michael Roberts and Sue Goldstein, children Lena, Mimi, Julia, Connor, Bryan, Lauren, and Andrew, and our parents with appreciation for their love, support and faith in us.

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Foreword

It is hard to find a topic in the field of human sexuality or pain where there are not already too many books. My typical reaction to a book proposal is that we do not need to rehash old ideas and data yet again; we need to produce some systematic new information or theories. When it comes to dyspareunia, I was dead wrong. As far as I can tell, there are no previously published (edited or authored) books on the topic of dyspareunia. This is an extraordinary and gaping hole in our scholarship and work. If you are not familiar with the impact of "sexual pain," read the chapters on the prevalence (Chapter 2) and relevance (Chapter 3) of dyspareunia and the physical and interpersonal suffering it causes (Chapters 5 and 31).

This volume is extraordinary in many other ways. Its comprehensive coverage of all aspects of dyspareunia research and therapy is unusual. It is not surprising that there are chapters on evaluation/assessment or on treatment options; this would be expected in most volumes of this type. It is also not surprising that there are three chapters on introital, vaginal, and deep dyspareunia. This reflects our current and somewhat limited understanding of how to classify the different dyspareunic syndromes.

It is surprisingly wonderful, however, to see the range of topics that the editors have included in their introductory, relevant aspects, and conclusion sections. As a former history student, I was overjoyed to see a chapter on the history of dyspareunia (Chapter 1). In the health sciences, we are constantly "reinventing" the wheel and forgetting what was previously learned. I was also very happy to see a chapter on the "Power of Patient Advocacy" (Chapter 38). The sad truth of this field is that we are not close to a cure and the importance of patient advocacy groups in providing support and information to the public and influencing those who control health care funding cannot be underestimated. Topics that have been ignored in the literature and clinical practice (e.g., postpartum dyspareunia, Chapter 34; cancer and dyspareunia, Chapter 33; genital

cutting, Chapter 36) receive attention in chapters written by experts. I was somewhat taken aback by a chapter entitled "Hidradenitis Supperurativa" (Chapter 10) because I had no clue what the term meant. I clearly have things to learn from this book even after working in this field for 20 years.

Not only is the coverage extraordinarily broad but so is the expertise. How many books have you seen that are co-edited by a psychologist, a urologist, and a gynecologist? I have been in a fair number of hospitals where these disciplines do not talk to one another let alone write books together.

Although each editor is already well known in this field, each brings a special type of experience and expertise to the preparation of this book. Andrew Goldstein is one the world's most perceptive clinician gynecologists when it comes to dyspareunia. Caroline Pukall has applied the methods of experimental psychology in innovative and striking ways to the study of genital pain. Irwin Goldstein has almost single-handedly shifted the focus of sexual medicine from a male-dominated perspective to a more egalitarian model. This multidisciplinary and multifaceted authorship encourages my hope that the new fields of sexual health/medicine will follow through on their stated goal of adopting a truly biopsychosocial perspective. In addition to the disciplines of the editors, there are chapters by epidemiologists, infectious disease specialists, physical therapists, lay patient advocates, neurologists, psychiatrists, and dermatologists. The message is clear: no one discipline has a monopoly on understanding dyspareunia.

Naturally, no book is without its faults, though I am hard pressed to find any serious ones in this volume. I could quibble with the medical treatment emphasis, which is not empirically based though I think this reflects current practice. I would have liked to see a chapter focussed on pain mechanisms, though this is dealt with in several chapters. I would have also liked to see a more life-span

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coverage of dyspareunia including separate chapters on dyspareunia in adolescence (Landry & Bergeron, in press) and postmenopausal dyspareunia (see Kao et al., in press).

Two chapters—"The Relevance of Dyspareunia" by Meana et al. and "The Future of Vulvodynia Research" by Foster—initially caught my attention because of their titles. I cannot remember the word "relevance" in many book titles. I also know that social and health scientists are abysmal at predicting the future of their own fields. Neither chapter, however, disappointed me; on the contrary, despite the fact that one was written by psychologists and the other by a gynecologist, they sounded remarkably alike. Both highlighted the need for improved classification/assessment and for the development of better outcome measures leading to more efficacious and empirically based multidisciplinary treatment. These chapters and the editors' preface all reflect the stridently biopsychosocial framework of this book. Hallelujah!

Basically, I am thankful to the editors who have put together virtually all of the world's expertise on dyspareunia into one volume. I will be proud to have this book on my shelf. There is little question in my mind that any clinician or researcher who is interested in dyspareunia will have to start here.

Yitzchak M. Binik, PhD

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Landry T, Bergeron S. (in press) How young does vulvo-vaginal pain begin? Prevalence and characteristics of dyspareunia in adolescents. *The Journal of Sexual Medicine*.

Preface

It's all in your head ... or is it? Historically, women have been told that the sexual pain they were experiencing was just that—in their heads. As soon as a woman complained to her health care provider about sexual pain, she was referred to a mental health professional, ignoring possible concomitant biologic concerns.

A total of 21% of women have sexual pain, but because it involves the genital region there is no one discipline devoted to the management and treatment of the pain. Providers have found it difficult to believe women's self-reports without objective testing. Today, we are studying the physiology of the brain with the ability to convert a descriptive field into one with outcomes assessment, including psychologic, neuronal, hormonal, and genetic testing. An animal model of genital pain for the purposes of researching pain assessment and management is now furthering our knowledge in the field. What was once considered purely psychologic can be paired with the biologic.

So how did the editors get involved in the study of pain? Andrew Goldstein started practice as a general gynecologist in 1998 with sufficient time with each patient to perform a review of systems including questions about the woman's sexual health: libido, pain, and orgasm. The number of women with sexual problems wanting help overwhelmed him. To gain further knowledge, Dr. Goldstein attended the Female Sexual Function Forum, the earlier name of the International Society for the Study of Women's Sexual Health (ISSWSH). There was little mention of sexual pain at that meeting. In 2001, while writing a chapter for the Johns Hopkins Manual on Gynecology and Obstetrics, Dr. Goldstein came across many references to vulvar pain written by a local practitioner, Stanley Marinoff, a leading vulvar pain specialist during the 1980s and 1990s. Dr. Goldstein spent time training with him and eventually took over his practice.

Dr. Pukall quickly realized that although sex was generally a forbidden subject, people had a lot of questions and misinformation about it. As a college and undergraduate

student, she took every human sexuality course available, until one semester her interest in psychology and sexual health coalesced. In 1995, after taking courses in psychophysics, pain, and human sexuality simultaneously, young Dr. Pukall offered to work in Yiczchak Binik's laboratory. Her work as a research assistant with Sophie Bergeron gave Dr. Pukall an opportunity to observe participants undergoing the cotton swab test and to speak with them afterward to learn about their experiences. Dr. Pukall was left wondering why they had such severe pain despite their healthy looking vulvas. It was at this point that Dr. Pukall recognized her interest in studying this taboo topic, to prove that the pain from which these women suffered was not purely psychologic, and to be able to give something back to them.

In 1998, with the appearance of sildenafil, Irwin Goldstein started receiving phone calls from women seeking help for their sexual dysfunction. A percentage of these women presented with pain and were referred to their gynecologists, who generally sent them back. Initially, Dr. Goldstein thought pain was related to either blood flow or hormones, and found that some women were helped with hormone therapy. After attending the annual meetings of the Female Sexual Function Forum and then ISSWSH and listening to presentations by Yitzchak Binik, Sophie Bergeron, Andrew Goldstein, and Caroline Pukall, Dr. Goldstein realized how much he had to learn about sexual pain. He decided to begin wearing loupes when examining women, allowing for better visualization of the painful genital areas. Having seen thousands of women with sexual problems, he concluded that there is nothing worse than sexual pain.

This book has been written to help those women in pain, to assist health care professionals in treating women with sexual pain, and to promote research in the field, with the intention of ultimately helping women who are suffering. The reader should note that there is overlap within the chapters because there is overlap within this field, rather

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than distinct categories of symptoms or disorders. Any redundancy is intentional, with the purpose in mind that it will make that chapter more understandable and meaningful to the reader than having to find that information elsewhere. In this way, the book parallels the field as biopsycho-social. It may be for this very reason that it has taken so long for a definitive text in sexual pain disorders to be written.

Woven throughout the book is the theme of effective management. What is effective management? Is it permanent—a cure—or a temporary treatment? For how long after treatment stops should the patient be symptom-free for the treatment to be considered effective? For many kinds of sexual pain, the only option is management that allows the woman to have decreased symptoms. In some cases, the only absolute cure may be surgery. This textbook presents the spectrum of treatments so that you, the practitioner, can choose the most appropriate and effective ones for your individual patients.

It is remarkable the alacrity with which this textbook has been produced. Andrew Goldstein and Caroline Pukall were perusing the books available at ISSWSH in February 2007, and discussed the need for a text solely on sexual

pain disorders in women. They shared their idea with Irwin Goldstein who readily agreed regarding the necessity for evidence-based information in this field. Authors were invited in October 2007, the contents were completed in May 2008, and first publication coincided with the February 2009 annual ISSWSH meeting. Despite there being several societies at which sexual pain disorders are discussed, this is the first evidence-based textbook of female sexual pain disorders in publication. In respect to the multidisciplinary nature of the book, its editors, and its contributors, the editors have proudly gifted all proceeds from this textbook to the multidisciplinary organization, ISSWSH.

The friendships of the three editors and respect they have for one another have deepened during the course of assembling this book. The editors, 10 associate editors, and dozens of authors involved in this project share a passion for the field of sexual pain and compassion for their patients who are suffering.

Andrew T. Goldstein Caroline F. Pukall Irwin Goldstein

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The editors wish to acknowledge the dedication and commitment of many colleagues without whom this project would have not been completed. In particular, we wish to thank the senior associate editor, Lara Burrows. We are indebted, as well, to all the associate editors of the book: Lori Brotto, Melissa Farmer, Gail Goldstein, Sue Goldstein, Arielle Metz, Leah Millheiser, Talli Rosenbaum, Kelly Smith, Katherine Sutton, and Denniz Zolnoun. We would also like to thank all the authors who took valuable time from their already busy lives to write chapters for this book, especially those who authored more than one chapter, demonstrating their dedication and commitment to the field.

In addition, we would like to thank Martin Sugden and Charlie Hamlyn of Wiley-Blackwell Publishing; Martin for having the foresight to see the need for this book, and Charlie for supporting us constantly. We would also like to express our appreciation to Brigitte Wilke who served as our development editor, seeing that authors' paperwork and deadlines were maintained, and providing guidance to us when necessary.

Last but not least, we all have people without whom each of us would not have been able to proceed with this project. Andrew Goldstein would like to acknowledge his office staff, Ruth Bradford, Tamika Hill, and Alice Hickling as well as his good friend and webmaster, Stan Felder. Caroline Pukall offers her thanks to her research assistants, Sasha Segal and Emma Dargie. Irwin Goldstein would like to give his appreciation to Sue Goldstein, Andrew Goldstein, and Caroline Pukall.

"I can no other answer make, but, thanks, and thanks."
—William Shakespeare.

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1

CHAPTER 1

Historical Perspective of Vulvodynia

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History of Vulvodynia

Vulvodynia, or chronic vulvar pain, is a syndrome that appears to have been recognized for centuries, but was not fully described until recently. It is thought that early Egyptian papyri, including the Kahun Gynecological Papyrus and the Ramesseum Papyrus, were the first texts to address gynecological issues including vulvar pain [1, 2]. The condition may have been described in ancient medical literature by Soranus of Ephesus, who referred to a condition similar to what we call vulvodynia today as "satyriasis in females" [3]. However, no documented, medically accurate descriptions of the condition appear in the medical literature until modern times.

History of the Term Provoked Vestibulodynia

Initial discussions of vulvodynia focused on the main complaint of women presenting to their physicians: dyspareunia (i.e., pain during sexual intercourse), a term coined by Barnes in 1874 [4]. In the late nineteenth century, Thomas [5] and Skene [6] described a condition of hypersensitivity in the vulvar region. Thomas [5] described this condition as an "excessive sensibility of the nerves supplying the mucous membrane of some portion of the vulva, sometimes confined to the vestibule... [and] other times to one labium minus." He noted that a primary complaint of women with this condition was dyspareunia. Similarly, in 1889, Skene [6] and Kellogg [7] reported that sensitive areas around the vaginal opening could cause problems with sexual intercourse. Very little new information on

dyspareunia was reported for a period of four decades, and then in 1928 the condition reemerged in the literature. Kelly [8] expanded on the damaging effects of vulvar pain on sexual intercourse, describing it "as a fruitful source of dyspareunia."

Information regarding the specific part(s) of the vulvar area implicated in the pain appeared later in published reports. Dickinson [9] found that almost 75% of his dyspareunic patients had a physical reason for their pain, with many suffering from problems of the hymen, urethral meatus, and fourchette. Hunt [10] stated that the minor vestibular gland structures had no link to the pain, and this claim was supported by Dickinson's report [9]. Over time, assertions regarding the cause of this pain began to appear in the literature. O'Donnell [11] believed that the cause of the pain was chronic inflammation attributed to an incomplete rupture of the hymen. Further supporting the involvement of inflammation in dyspareunia were the reports of Pelisse and Hewitt [12], Davis et al. [13], and Woodruff and Parmley [14]. For example, Pelisse and Hewitt [12] found histopathological evidence of chronic and acute inflammation in the posterior vestibule of affected women. Names for this condition, reflecting the role of inflammation (-itis), began to emerge and included the following: focal vulvitis [15], vestibular adenitis [16], focal vestibulitis vulvae [17], and vulvar vestibulitis syndrome [18].

The term *vulvar vestibulitis syndrome* (VVS) is commonly used to describe a condition in which localized, provoked dyspareunia is the main presenting complaint. According to Friedrich [18], the diagnostic criteria for VVS are "severe pain on vestibular touch or attempted vaginal entry, tenderness to pressure localized within the vulvar vestibule, and physical findings confined to vestibular erythema of various degrees." Today, the relevance

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