TWELVE

The Complexity of Integration and the Clarity of Collective Consciousness: The Development of a Model for Research Training in the Sexual Pain Disorders

Marta Meana, PhD
University of Nevada, Las Vegas
Sophie Bergeron, PhD
Université du Québec à Montreal
Yitzchak M. Binik, PhD
McGill University, Montreal

OVERVIEW

It has been an interesting exercise to formalize the process characterizing the sexuality research activity that has engrossed us for years. This self-reflection on a model we were too busy implementing to consider much more than an organic, data-driven development has led us to assert our collective commitment to certain principles and their power to shed light on the sexual disorders. Keeping in mind that the retrospective imposition of order on the past always lends it a questionable measure of deliberateness, we will describe (1) the sequential development of our research efforts and training, (2) the paradigmatic principles that guide us and (3) existing training challenges. The "we" used throughout is primarily that of two graduate students who trained under this model and then moved on to faculty appointments of their own (the first two authors) and their mentor (the third author), but is also used on behalf of other graduate students and collaborators who have been integral to the research team. The team is comprised of Samir Khalife, Caroline Pukall, Elke Reissing, Deborah Cohen, Howard Glazer, Kelly Pagidas and Fran Abbott.

LATERAL EXPANSION AND VERTICAL NARROWING: THE DEVELOPMENT OF A TRAINING MODEL

From its inception in 1981 the Sex and Couple Therapy Service established at Montreal's Royal Victoria Hospital by McGill professor Irv Binik brought together psychology and psychiatry to tackle the problems of sexual dysfunction and marital distress. In its function as both a community clinic and therapist training center, the service functioned under the assumption that the more perspectives brought to bear in the investigation of a problem, the better. And thus this group of psychologists, psychiatrists and interns from clinical psychology and sexology programs around the city worked together on cases, presenting them at rounds and exposing any approach to scrutiny and questioning. Cognitive-behavioral and psychodynamic approaches were made to answer to each other and both had to address the growing press of pharmacotherapy. The result was a hypothesis-testing approach to clinical work that we believe served both our clients and our trainees well. This approach was also rich in generating hypotheses that would guide our research efforts for years to come.

Within this context we started seeing an increasing number of women presenting with dyspareunia. They were generally referrals from gynecologists who could not find any obvious pathology and assumed the problem to be psychosexual. Our assessments, however, did not reveal any obvious psychological pathology either. Sure, there was distress about the pain, relationship problems and deficits in other aspects of sexual function, such as desire and arousal, but were these precursors or sequelae of the pain? Thus our first research question in the sexual pain disorders grew directly from our clinical work. That symbiosis of practice and research would become a defining pattern in all future investigations.

We embarked on an initial study to investigate potential etiological factors in the development of dyspareunia. Our aims were to conduct an indepth pain assessment of women with dyspareunia and compare them to a matched no-pain control group on all the factors that the largely anecdotal and case study literature had assumed to be etiologic. Rather than draw from our sample of women seeking therapy at the service, we threw a wider net into the community and placed advertisements searching for women who experienced pain with intercourse. To our amazement, we were inundated by calls, and within two weeks had screened and found 125 women who met criteria for the study. Clearly this was a common problem that was not being resolved with any great success.

Continuing and expanding our initial commitment to the benefits of a multidisciplinary approach, we integrated gynecology into our comprehen-

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sive psychosocial and pain assessment protocol. In the search for etiologic clues we had added pelvic examinations, ultrasounds, colposcopies and a number of relevant cultures. Our findings were to radically change the way we viewed the sexual pain disorders. In our small research corner of the world, it did, in fact, amount to a paradigm shift.

First, comprehensive pain assessments showed us that the characteristics of the pain were more predictive of gynecologic findings than were the psychosexual variables comprising sexual dysfunction classification systems. The implication was significant. Perhaps our historical emphasis on the sexual aspects of this problem had paradoxically eclipsed the presenting complaint – pain. Perhaps an examination of the pain could yield more valuable clues to the etiologic mystery of dyspareunia than could an examination of sexuality. Inarguably, the results indicated, at the very least, that a study of the pain involved in dyspareunia could be much more fruitful than it had ever been assumed, considering it had literally never before been systematically investigated.

The second important finding from this preliminary study was that women with dyspareunia and no-pain controls differed on very few variables other than those relating to sexual desire, arousal and the experience of pain during gynecological examinations. Women with dyspareunia did not display higher levels of psychological symptomatology, they did not have worse marriages, they did not have a higher incidence of sexual abuse or assault, they did not suffer from sexual aversion and they were not more prone to somatization. They looked much like women with no pain, except for the fact that sex hurt them and that they were not as interested in engaging in it or as aroused when they did so. Again, our study methodology was not equipped to determine whether the lack of desire and arousal preceded the pain or not, but it seemed reasonable to entertain the possibility that these women were simply not raring to engage in a painful activity.

The other important way that women with dyspareunia differed from those without was in terms of the gynecologic findings. Eighty percent of women with dyspareunia reported a specific and reliable pattern of pain upon gynecologic examination. Fifty percent of them appeared to have a hyperalgesic area at the introitus of the vagina that reacted to the slightest touch without vaginal penetration and that fit the criteria for vulvar vestibulitis. At this point we were starting to see the psychosexual explanation for dyspareunia slip between our proverbial fingers.

While we were investigating the etiology of sexual pain we felt the very real press for effective treatments. Women were suffering and they could not wait for the many years it could take research to definitively find the cause(s) for their pain. This led our team to conduct treatment studies on the effectiveness of treatments for vulvar vestibulitis, the most common type of dyspareunia in our first study and in pre-menopausal women. The first of these studies was a retrospective follow-up of women who had had vestibulectomies. Over 60% of women reported a successful outcome as defined by pain reduction and increase in sexual activity. This study and a growing literature supporting surgery empirically gave us confidence to conduct the first randomized controlled treatment outcome study for vulvar vestibulitis.

Our pattern of extending our investigations to include other potentially informative disciplines continued. The three treatments compared were vestibulectomy, group cognitive-behavioral pain management and pelvic floor biofeedback. Much as was the case in our first etiologic study, the recruitment of women with pain posed no dilemma, as they were numerous and desperate for information and treatment – so much so that the ordinary reticence to random assignment, especially with a surgery condition, seemed to be a minor issue.

At 30-month follow-up vestibulectomy had outperformed the other two conditions in reducing pain, but cognitive-behavioral therapy had performed just as well in terms of sexual function and psychological adjustment outcomes. The thorny issue of appropriate outcome measures had just become another theoretical and methodological issue to add to the many questions guiding our research effort. How should a successful outcome be defined? A reduction of pain or an increase in sexual function and satisfaction? And more intriguingly, why did a reduction of pain not reliably lead to increased sexual activity? The questions were multiplying and we knew there was much work to be done.

Our inclusion of pelvic biofeedback as one of the treatment conditions had been guided by some preliminary work in the area and by two theoretically grounded hypotheses. First, it might be reasonable to expect pelvic floor hypertonicity in women with vulvar vestibulitis, at least as a conditioned response to painful stimuli, if not more. Second, vaginismus was defined in the DSM-IV as a sexual pain disorder characterized by a muscle contraction that had never actually been tested. Thus halfway through the treatment study we swung back into etiologic mode and compared women with vulvar vestibulitis, vaginismus and no pain at all. Women with vaginismus showed an average muscle tension significantly higher than that of no-pain controls. Attending to the muscle tension in women with

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vulvar vestibulitis seemed warranted. The data also supported questions we had already raised regarding the real distinction between vaginismus and dyspareunia. Were they qualitatively different disorders or was it all a question of degrees – degrees of hypertonicity and behavioral avoidance?

Having found the pain of dyspareunia to be as central to predicting potential etiologies as we had in the first study, there was little question in our team that we also needed to focus on this issue in as scientifically rigorous a fashion as possible. Drawing from the basic science pain literature indicating that sensory changes occurring in pain syndromes is often suggestive of mechanism, we set out to investigate vulvar tactile and pain detection thresholds in women with vulvar vestibulitis. Using the von Frey type hairs in a precise pain-mapping protocol we found that women with vulvar vestibulitis demonstrated lower tactile detection and pain thresholds at each vestibular site tested and in the labium minus but in no other non-genital site. This was clearly not generalized pain sensitivity but a very specifically located one. We also now had an intricate and reliable outcome measure for future vulvar pain studies.

Our interest in the pain of the sexual pain disorders is now taking us in novel new directions as we expand our disciplinary field to include neurology. We are in the process of testing women with vulvar vestibulitis with fMRI equipment in an attempt to determine whether this type of dyspareunia has a specific pain signature in the brain in the fashion of many other pain syndromes.

But again, treatment cannot always wait for etiology to be determined, so we continue to investigate other ways in which our preliminary, but by no means definitive, etiologic findings might suggest possible treatments. Studies under current consideration and design involve acupuncture and hypnosis - methods that have shown some success with other syndromes. We are also looking closer at the potential mediating effects of cognitive factors, from pain hypervigilance to the impact of women's own causal attributions for their pain. Their potential usefulness in cognitive-behavioral interventions is compelling. Our team has also started to expand geographically. The first author is now a professor of psychology at the University of Nevada, Las Vegas, where she has established a gynecologic pain clinic, and the second author is professor of sexology at the University of Quebec, Montreal, where she also conducts research and trains students at a vulvar pain clinic. The third author remains where it all started at McGill University in Montreal, leading a steady stream of bright young graduate students toward the collective goal of solving the puzzle of the sexual pain disorders.

The pattern we see in this chronological exposition of our progress is one of a lateral expansion of different parallel levels of analysis, from psychology to psychiatry to gynecology to physical therapy to pain measurement to neurology. Concurrently, we see a narrowing of our research foci from general etiological factors for women with dyspareunia in general to the definition of dyspareunia subtypes to a concentration on vulvar vestibulitis to an investigation of more micro-level questions about the characteristics of pain and hypertonicity and finally to a brain activity signature possibly distinguishing one kind of intercourse pain from others. It is hard to know for sure whether that pattern was our intent from the outset. Retrospection is always a tricky affair. But it most definitely has become our quite-conscious modus operandi in the last few years.

THE THEORETICAL/PARADIGMATIC PRINCIPLES GUIDING THE TRAINING MODEL

The aforementioned research trajectory was also a training trajectory. With the exception of the third author and some collaborating faculty, graduate students primarily conducted the work. The faculty-student collaboration resulted in the best type of training: one in which everyone learns from everyone else. But was there a training model or were we simply reacting to the latest results once having launched the first question? It depends how you define model. If it means that you work within a framework of inquiry that values certain parameters as essential to research and, if you can delineate these with little effort, then we definitely had and have a model. There have been a number of different personalities on our team and, despite the occasional difference in perspective, we think we can safely state these guided us all. So, here they are:

The everyday application of the scientist-practitioner creed: There has been a lot of ink expended on the merits of using clinical practice to inform the work of science and vice versa. We will not expend any more to extol its virtues but we will state that we followed it religiously. This entire programmatic line of research grew directly out of 10 years of clinical practice. Every student in the program has conducted clinical work with the very population they have been researching. Many of our hypotheses, major and minor, have grown directly out of this work and the majority have borne scientific fruit. In one sense that is no surprise, as they were hypotheses born of the real experience of individuals (our clients) rather than the abstraction of a late-

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night hunch in the laboratory. But perhaps more importantly, the direct link between the research questions and the clinical cases gave the research a face, or rather, many faces. Ours has not been work about a theoretical abstraction that maybe some day would help someone somewhere. Our work has had the potential to help real people, people we have treated, people we are treating and people we are yet to treat. This direct connection has imbued both faculty and students with a passion and commitment that can often be lost in the daily grunt work of research. The students in this research team have been extraordinarily driven and devoted.

The biopsychosocial perspective: There has never been a question in the team's mind as to the potential complexity of the sexual pain disorders and of the numerous intertwining feedback loops that tie together the physiological specifics with psychological and social ones. We are, after all, dealing with a pain that involves sexual activity. Pain aside, sex is essentially a physiological event that occurs in the context of an individual's feelings about self, other and sexuality in general. And all of this happens within a broader sociocultural context that imposes scripts, norms and gender role expectations. For good measure, add the element of pain. It simply does not get any more complicated than that. Omitting one part of that equation in our conceptualization of the problem has never been an option. Clearly not all studies can reasonably incorporate all of these aspects, but results have always been integrated into the larger biopsychosocial framework that guided the overall research effort. When students have occasionally veered off in one direction, the whole picture is always held up as the beacon, lest we forget the interactions awaiting whenever we bring it all together.

The biopsychosocial perspective has necessitated the active use of *multidisciplinarity*. We knew we needed to recruit different specialties into our research to be true to that perspective. In the early days of the Sex and Couple Therapy Service we started by collaborating with psychiatry, but as our research and training model evolved we incorporated gynecology, cytology, pathology, physical therapy, pain specialists and neurology. We keep adding to this list, as we now start collaborating with hypnotherapists and acupuncturists. An integral part of the training model is to teach our psychology students to interact and work collaboratively with all of these professionals. This is not a simple matter of interpersonal skills. It requires the students to become familiar with the work of these other disciplines. It requires them to acquire information outside their stated curriculum, so as to become sophisticated participants in the design of those aspects of their research that

fall outside the realm of their primary expertise. Our students have attended gynecological examinations, discussed culture results, designed physiological devices to measure pain, learned how to use complex equipment measuring pelvic floor tension, attended vestibulectomies (sometimes queasily) and learned how to interpret MRI results. Aside from the obvious research applications, this kind of training has won them the respect of collaborators from other disciplines and given them the breadth of knowledge to critically assess the research of other disciplines into the very same disorders on which we focus.

Implicit in the biopsychosocial perspective and its attendant multidisciplinarity is the rejection of dichotomization. The literature we reviewed was striking in its dichotomized presentation of the problem. The burning question seemed to be, "Is the pain psychological or physical?" And that was how women with the problem were treated by the health care delivery system. If the gynecologist found no obvious pathology it was assumed the problem was psychological and vice versa. This was hardly surprising as our classification systems reinforced the dichotomization in their very diagnostic definitions (psychogenic or not). This dichotomous language is simply not permitted in our lab. Everything we know about sexuality (not to mention everything else) tells us it cannot be that simple. Whenever any one of us falls into this way of speaking about the problem (and everyone at some point has), we all have a license to call each other on it. We are not going to work that way. Even more ambitiously, we are not going to think that way. It has been a type of deprogramming that has taken more effort than one would think, but it has been crucial to our research and it is an important training principle.

A non-dichotomous, biopsychosocial, multidisciplinary effort amounted to one thing: an *embracing of the complexity* of the problem. No single causal pathways here. No quick fixes. No one-trial miracle recoveries. There was not going to be one key that opened up this vault. It was going to be a combination that differed, sometimes slightly and sometimes dramatically, from individual to individual. If there ever was an area that demanded a high tolerance for ambiguity, this was it. Students will often fight this type of conceptualization, partly because it is frustrating and partly because they wonder if maybe no one brilliant enough (or not so much as they) has addressed the issue. Hubris is not all bad in the ambitious graduate student, but our training model tries to instill a fascination, rather than a resistance, to the complexity of the problem, while not quashing individual dreams. We think it makes for more careful researchers and clinicians and raises the probability of success.

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Not all studies can investigate all potential aspects of the problem, but our training model encourages an *investigation of interactions* in research whenever possible. Even when a study can only focus, for methodological or respondent-burden issues, on one or two questions, we keep in the back of our minds a future integration of these questions into a larger study that can accommodate them. It is like a puzzle. Sometimes you can only work on one corner, but you know at some point that you will have to join it to the whole in a meaningful way. While in research we train our students to consider and then test all possible interactions, we train them to *assume interactions in clinical practice*. This is a therapeutic stance that can only help. First of all, the general pain literature empirically supports the mediating effect of many quality-of-life factors on the experience of pain. Second, even if a reduction of distress in one area of the client's life does not ameliorate the pain, the resolution of a problem is never unwelcome, despite the fact that it might not have been the primary goal of the therapeutic intervention.

Finally, a collective consciousness is the one other important principle that characterizes our training model. Collective consciousness in research is defined as a situation in which research supervisors and graduate students share the same object of research (Bennich-Bjorkman, in press). This does not imply that we are all working on the same research questions, but that our questions are all closely connected, that the answer to any one has the potential to inform all other questions. This makes us all dependent on each other and thus supportive of each other. The result is a far-flung collaboration where even the editing of a fellow student or colleague's work is not experienced as an imposition done in charity or to gain favor, but as useful information with a high probability to further your own research project. The creativity and productivity potential of such a model has already been shown in the literature to surpass that of research teams with a more individualistic consciousness. To this day we continue to circulate everybody's half-baked ideas and products for the scrutiny of all. The process can sometimes be painful and plodding, but the pain is spread around equitably and rapidly loses its potential for narcissistic injury. The final products are always the better for it.

CHALLENGES TO THE RESEARCH TRAINING MODEL

Many of the aforementioned theoretical/paradigmatic guidelines of our training model present challenges in and of themselves, but they are internal ones that we can all collectively target and work on. There are, however,

some external challenges to the training model and to this type of research in general. Our control over these is limited.

The first that comes to mind is the general acceptance of the paradigmatic shift of the sexual pain disorders from psychosexual dysfunctions to pain disorders that happen to impact on sexual function. The research literature is starting to incorporate this new perspective, but change is always slower in that group of health care providers whose training predated this work. Lack of physical pathology still leads many physicians to conclude that their patients with sexual pain have a psychological problem, despite the widespread acceptance that other types of pain without apparent tissue damage are not "psychiatric" (e.g., migraines, lower back pain). For lack of other evidence, women themselves start becoming convinced that their pain might originate in some psychosexual or relational conflict. It is going to take some time before the world stops assuming the connection between the sex and the pain as anything more than incidental in the majority of cases. Tennis elbow does not make tennis players wonder whether they really like the game. Orthopedic surgeons do not suggest the idea of a deep-seated psychic conflict with the act of holding a racket and hitting a

But the problem permeates the very language we use. Even our research team has to refer to these pain disorders as sexual pain disorders so that our audience/readers can immediately know we are referring to dyspareunia and vaginismus. And yet the implication remains that there is such a thing as sexual pain and not just sex that happens to be painful. This represents a dilemma in which you sometimes have to sacrifice some degree of accuracy for ease of communication. We are willing to do that, but we always worry that we might be perpetuating the problem by the very words we use.

Another challenge to our research and training is that of convincing health care providers, funding agencies and even other psychologists and psychiatrists that the problem of the sexual disorders is a serious one. Most are surprised to learn that the prevalence of dyspareunia is in the 12-14% range, as these disorders are grossly underreported. In addition, because of their inevitable connection to sexuality, the sexual pain disorders are often treated as minor annoyances that cannot possibly result in that much damage. They are not life threatening and the pain is not chronic – they are recurrent, only flaring up with sexual activity. They are considered to simply complicate sexual activity, yet, paradoxically for a popular culture that is so focused on sex and desirability, this is considered by many health care pro-

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fessionals to be less than concerning. A psychiatrist approaching the first author after a paper presentation on our research joked, "Oh come on, dyspareunia is better than no pareunia at all!" Apparently the women in our studies do not agree. Many have stopped having sex altogether; they have a high level of distress about the problem, it has changed the way they feel about themselves and their frustrated partners and their relationships are suffering the effects. Perhaps the cavalier way in which many professionals and some of our colleagues view the sexual pain disorders is a function of a general discomfort with topics relating to sexuality. It is difficult to know, but we, as well as our graduate students, have all encountered the attitude that we are working on an area of inquiry that is somewhere outside the realm of the truly important.

In terms of funding, we have been relatively successful, but it remains a challenge to get money for sexuality research in general. You pray for the occasional topic-specific request for applications because you suspect that if you submit a grant proposal to the general pool there is a very good chance you will be up against studies on disorders that reviewers consider more serious than the ones we investigate. The availability of funds for sex research tends to be tied to political and cultural factors that wax and wane over the years. If we can succeed in eventually convincing federal funding agencies that sex is an important aspect of both physical and mental health rather than a frivolous secondary consideration in the quality of people's lives, then maybe one day funding for sex research will stabilize at a reasonable level.

Since we began our work on the sexual pain disorders we have conducted all of our studies with clinical populations and involved various health care disciplines. Despite the fact that the majority of sex research is conducted on college student samples, we feel strongly that this is not an ideal sample for our work. However, the challenge of working with clinical populations is a significant one. They are not as easily accessible and the cooperation of other health professionals is often necessary to work with these populations. This can sometimes also mean that institutional board approval is necessary from more than one institution, each with differing standards of what they find ethically acceptable. Furthermore, conducting studies with clinical populations often requires that you offer clinical services for those in need, even if that does not constitute the focus of your investigation. This represents a real risk to the timeliness of students' dissertation projects.

One final major challenge to our training model has been to engage in both etiologic and treatment research simultaneously. Our training is deeply

rooted in the scientific tradition of exhausting inquiry before any connection between factors is pronounced. Yet, in light of the suffering of the women we see both in our studies and in our clinical practice, this seems a luxury lacking in compassion for those who are in distress in the here and now. Our compromise has been to continue our etiologic inquiry while simultaneously engaging in treatment studies that employ interventions with some theoretical or empirical support, despite our not fully or even partly understanding the mechanisms by which they would effect a reduction in pain. Our treatment study of vestibulectomy is a case in point. We conducted that treatment study because we had data that indicated that a majority of women had reported improvement in a retrospective study. Did we understand why the removal of a small piece of vestibular tissue with no apparent pathology would reduce or even eliminate pain? No. But we could work on the "why" later. More pressing than our scientific curiosity was the relief of pain in women whose lives were so adversely affected by it. Although there is a long tradition in medicine of empirical treatments, we have to admit that it was initially a challenge for us to make our scientific need for understanding take second place to the more immediate needs of women who cannot wait for our future discoveries. Since then, the relief of pain in many of them has convinced us that this is the way to go - to run parallel etiologic and treatment studies.

FINAL REMARKS

The sexual pain disorders pose many research training challenges and opportunities, some of which we hope to have shed light on in this monograph. We think our training model attempts to stress some among the most important hard principles of science while marrying these to the most pragmatic and compassionate of clinical practice. The value of our results thus far and in the future, only time will judge; but we hope we have, at the very least, taken the sexual pain disorders out of a vestigial conceptual arena that considered them psychosomatic manifestations of psychic conflict. In the process we also hope that we have trained and continue to train a host of graduate students to embrace the complexity of human existence, no matter what wrench is thrown into their dissertation analysis and results section.

Some folks may think we are engaged in research and training on a very narrow slice of human life. We beg to differ. We believe that the sexual pain disorders, in all of their frustrating complexity, are an apt analog for

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any number of human activities that involve the body, the self, the other and culture. Training students in this complexity is not easy for them or for their supervisors, but those still left standing, or rather thriving, have their hand on the pulse of existence in all its glorious and maddening configurations.