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SIECUS REPORT

Emerging Issues in Women's Reproductive Health

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Martha E. Kempner, M.A.
Director of Public Information

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WOMEN'S HEALTH ISSUES: THE PERSONAL, THE MEDICAL, AND THE POLITICAL

Martha E. Kempner, M.A.
Director of Public Information

For most *SIECUS Reports* we pick a very specific topic and examine it closely. In recent issues we have looked at Marriage and Sex Workers, and, of course, each year we examine sexuality education. Issues like this, however, often turn out to be some of my favorites because we have so few limits. For this issue, we simply wanted to explore important issues in women's reproductive health. The possibilities for topics were endless and changed constantly throughout the planning process.

We chose the final articles because they represented a wide range of topics and perspectives. All of the subjects we chose to focus on are related to public health; some are widely discussed, some controversial, and some are relatively unknown. And the authors approached their subjects from very different angles; we have the personal, the political, and the medical.

A MOTHER'S PERSPECTIVE

When we decided to devote an issue to women's reproductive health, we knew we wanted to address HIV/AIDS. HIV is a huge threat to women's health, particularly young women and African-American women. In 2001, HIV infection was the 6th leading cause of death among all women ages 25-34 and the number one cause of death for African-American women in that age group. Women's risk for this disease are increased due to biology, socioeconomics, and inequality. Due to biological factors, a woman is approximately twice as likely as a man to contract HIV during vaginal intercourse. The Centers for Disease Control and Prevention explains that "socioeconomic problems associated with poverty, including limited access to high-quality health care and higher levels of substance use, can directly or indirectly increase HIV risks." The CDC also states that women are less likely than men to receive medical attention such as antiretroviral therapy. And, women in the U.S. and around the world are often not in a position to insist on condom use with their partners.[1]

Despite these overwhelming statistics, the issue of HIV in women is often ignored in the United States. Who can forget Vice President Dick Cheney's admission, during the 2004 debate, that he wasn't aware that there was an epidemic among African-American women in this country? Although there are clearly many angles we could have taken to explore this issue, we chose to take the personal. Dr. Patti Britton, a clinical sexologist in California and former editor of the *SIECUS Report*, details her account as a mother watching her daughter suffer with HIV/AIDS during the early stages of the epidemic. Britton's story shows that many things have changed since those early days—she wrote her first article on the topic anonymously—and yet when it comes to women and AIDS, many things are still the same.

THE PUBLIC HEALTH AND THE POLITICAL

We then move our focus from the personal to the political to look at two issues in women's reproductive health that seem to be caught in the intersection where public health and public policy meet—HPV and emergency contraception.

HPV (human papilloma virus) could be described as simultaneously the most widespread and the most misunderstood sexually transmitted disease (STD). Although the majority of genital warts are too small to see, school students across the country are treated to slide after slide of cauliflower-sized growths and told to expect this if they become sexually active. They are then led to believe that HPV inevitably leads to cervical cancer when in truth only a small percentage of HPV infection has the potential to cause cancer, and regular screening with pap smears can treat these infections before they become cancer.

Perhaps the most common misperception about HPV is that condoms provide no protection from this disease. Despite research to the contrary, this myth has been deliberately perpetuated by conservative forces who wish to denigrate condoms in order to argue that unmarried individuals have no choice of protection but to remain abstinent. And to further limit prevention options, these same forces have questioned whether the forthcoming vaccines should be given to young women on the grounds that complete protection might encourage promiscuity. In this issue, Deborah Arrindell and Fred Wyand of the American Social Health Association try to separate fact from fiction and explain the truth about HPV.

Similar arguments are used in the fight against Emergency Contraception (EC), a form of birth control that can prevent pregnancy if taken within 120 hours of

unprotected intercourse. The potential to reduce unintended pregnancy and abortion is well documented, and the need for quick and easy access is unmistakable, yet the FDA has been dragging its heels on a decision to grant over-the-counter status to one brand of EC. In her article, SIECUS' Jennifer Heitel Yakush takes us step-by-step through this controversy and the countless political maneuvers that continue to impede progress in women's health.

We have also included a brief scientific piece by the Population Council explaining research that sheds new light on how EC really works. Opponents frequently argue that EC is an abortifacient because it was once believed that if taken after fertilization it would prevent implantation. This new research, however, shows that EC acts only to prevent ovulation and does not impact implantation at all.

Finally, we are thrilled to include an essay by columnist Katha Pollit, entitled "Virginity or Death," that originally appeared in *the Nation*. Pollit argues that the fights over HPV and EC are less about health and more about sex, specifically women's sexuality. She puts voice to what many of us in the public health field have been saying as we watch these debates unfold—the arguments being thrown about are simply smokescreens under which conservative social values masquerade as public health concerns.

A MEDICAL PERSPECTIVE

We then move to a medical perspective from which Caroline Pukall writes about a hidden problem among women. Many people have never heard of vulvodynia, yet it affects approximately 16% of women. Characterized by chronic pain of the vulva and vagina with little or no explanation, vulvodynia is often misunderstood and misdiagnosed. Women who seek medical attention for this problem are commonly subjected to numerous invasive and unpleasant tests only to be told that it is all in their head. In her article, Pukall explains the difference between vulvar vestibular syndrome and generalized vulvodynia providing research on the symptoms, cause, and treatment for each. She also explores the physical and psychological experience of women suffering from vulvodynia and the impact on their sexuality and sexual relationships.

SIECUS REPORT NEWS

I am so excited about this issue, that it makes it even harder to announce that we have recently made the difficult but necessary decision to discontinue publication of the *SIECUS Report*. SIECUS remains dedicated to providing you with timely information and analysis related to all aspects of sexuality and sexual health; unfortunately, our limited resources prevent us from continuing to sustain this quarterly journal. We will publish one more issue after this to close out Volume 33. All past issues of the *SIECUS Report* will be available on our website.

I have been working on this journal for almost five years and have served as editor for two, and I have to tell you that it has been one of the most challenging and rewarding parts of my job and a product that I have always been, and will always be, proud of.

References

1. *Fact Sheet, HIV Among Women* (Atlanta, GA: Centers for Disease Control and Prevention, National Center for HIV, STD, and TB Prevention, 2004), accessed 5 November 2005, <http://www.cdc.gov/hiv/pubs/facts/women.htm>.

FOURTEEN YEARS LATER— A MOTHER'S STORY REVISITED

Patti Britton, Ph.D.
Clinical Sexologist
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Fourteen years ago, in Vol. 20 of the SIECUS Report, I wrote an anonymous story about discovering my daughter was HIV+ and the tragic family issues that ensued. That story received a lot of attention at a time when learning you had HIV was akin to a death sentence. This update, after the death of my daughter last fall, is my story now with full disclosure for others who may feel the need to hide behind their shame and secrecy. It's time for us all to speak up and speak out.

Mothers' Day Questions

"Happy Mothers' Day"…the words shatter like giant glass snowflakes down into a long, dark, hollow well.

"Thanks, honey," I quietly sputter out the words to my partner. "But, I don't know if I'm still eligible. Can you still be a mother when your only child is gone?"

Gone: a tidy word for death. The D word was banned by my Mothers' group in New York City in the 80s, during one of the many crisis times on this journey now complete. "No D spoken here" was their motto, hiding nicely inside their cocoon of denial, hoping that it never would be a word spoken about *their* child living with AIDS. Waiting and wondering were my constant companions then. My daughter, a white heterosexual, non-IV drug user, became infected with HIV as a confused teenager experimenting with sex in Mnahattan, the epicenter of the early AIDS epidemic, maybe 20 years ago.

A lot has happened since then: since the early 1980s, 20 million lives have been taken by HIV/AIDS, " a figure that surpasses any single cause of death in modern history."[1] 42 million people today have AIDS[2], 19.2 million of them women,[3] and for the very first time the United States has just passed the one-millionth mark in cases of HIV/AIDS. Sadly, as the mothers of every person with HIV/AIDS, I am among the many of us who no longer have living children. If we were to look at the statistics from Uganda and AIDS[4], we would see that more than one half (56%) of the population of women ages 25-29 and 29% of those 15-19 are infected with HIV and will die of AIDS. We live in an illusion that we in the U.S. are safe and free from such harm. Unless we address the growing numbers of women who cannot use the new "magic bullet" approach in medications, for one or more reasons, such as my daughter's inability to stay on a maintenance program of drugs, we will see more women in this country become these staggering statistics as well.

As their mothers, we are the remainders, the unsung victims of the post-sexual revolution, an era escalated by the spread of this disease first noted among gay men, then bisexual men, then heterosexuals, then women. Now my daughter, a survivor of HIV/AIDS for almost 20 years, is a memory in 158 photographs pasted across the poster boards that sat in front of her memorial funeral service as a reminder of her life, while I question if I, her mother, am still eligible to wear the mom mantle.

Maybe we need another word. How about AIDS *"madow"* (pronounced like play-doh)? Half maternal, half widow, we face a loss so great it's hard to bear or describe. But I have a personal quest: to tell you what it's like to ride the horrific roller coaster of living with AIDS as the mother of a Person Living With AIDS (PWA), to tell you what it's like to live to see your child die of this horrible disease, up close and personal, to the cellular level of intimate connection. It's almost unimaginable how a mother could end up watching a grown 30-something woman, her only child, shrivel up to a whisper of a wracked, wretched body and not recognize her for the 90-year-old skeletal self she resembles as she gasps through her last weeks of life or what it's like to be sitting by the side of her dying grown child, holding her fragile hand until her last human breath.

Each of those 42 million people with AIDS and the millions yet to be counted, had or has a mother, it is for those mothers that I tell my story of grief and recovery. This is also my daughter's story and the story of how we as AIDS *"madows"* cope and thrive, despite our hideous loss. And, perhaps just as important, it is my prayer to help others recognize that this is a worldwide tsunami that's taking victims in the millions, especially women, and that this is the moment to care and do something about it before it's really too late.

PUTTING A FACE ON AIDS

On August 25, 1968, my daughter Holliday was born to me, a single mother in New England. At that time, it was not fashionable to bear a child and not be married. Those were the days of "illegitimate children" and scorned unmarried

moms. But, being a rather unconventional woman of my times, I wore my Scarlet Letter with pride, knowing that a revolution was brewing, giving single women the right to be single moms, without the shame.

We lived for a year with my parents in a suburban town and shortly after that, with great support from them to care for a newborn infant, I decided to return to college and moved to Johnson, Vermont. At age two, Holliday began day care and early schooling. She was a clown, a perfect mimic, and a consummate comedian. People loved her lightness and silly ways. She was a typical kid, wearing her white undies on her head for hats and slurping spaghetti from the bowl until the strands filled the small kitchen we shared with one of my four sisters while we both attended college.

I loved those years, taking care of my daughter, watching her grow and thrive, and getting my own ducks in a row to be a good provider. Her early years would never have been so easy without the constant love and assistance (babysitting, a little cash now and then) from my loving parents, her "grams." She had funny names for everyone and the uncanny gift of being able to imitate anyone to a tee. She was a born performer. In fact, she began to play an instrument at an early age, following in the footsteps of her aunt, who was a mere 18 months older and who to this day is a virtuoso violinist. Those two were a born pair, more like sisters, and spent hours together in shared fun.

Holliday attended private alternative schools in kindergarten and elementary-level grades, with this non-traditional single mother dedicated to the finest education. She played the trumpet in school bands, which was a coup for a girl at that time. Always, she remained jolly, a light spirited girl, eager to grow and learn.

After college, I worked for the Vermont Planned Parenthood statewide affiliate for several years and kept an open dialogue with Holliday at every step along the way. I remember times when she would be in our VW bus, filled to the brim in the back with condoms and books for my rural family planning outreach travels. Once I hit the brakes too hard and all the condoms tumbled out at an intersection, which gave us red faces and afterwards hysterical laughs at how so-o-o many cars stopped to gape at what was in the road. Another time, I recall her helping us at the PP office to pop the expired pills out of their cases. Over the years, she played many other roles as an eager participant in the world of sexology.

As she was blooming into a pre-teen, we moved from the comfort of family and friends, a small world of being known, to the borough of Queens, New York. Her humor and gentle approach to everything was contagious. We had a wonderful time adjusting to our new lives and thanks to an aunt in Manhattan who allowed us both to enjoy a cultured life, we began to enjoy our new times together in the city. That was short-lived.

We lived far from the office of National Planned Parenthood and from the cultural and social events, and commuting into the city became a strain. A good friend gave us a tip on an affordable rental on the Upper West Side of Manhattan, a residential hotel which we dubbed "Greystone Manor." We joked repeatedly about how we should write a sitcom script about its people and dramas that we watched taking place there. We had a good time, and she began to play her trumpet in a competitive junior high school band. It was a joy to watch her attend that school. She thrived, doing well in her academic classes, keeping up with her trumpet practice, and blossoming into a beautiful young woman. When high school came around, she competed for the performing arts high school, and out of 3,000 was one of the 300 picked. I was so proud. I had high hopes for her to develop herself and perhaps apply to one of the musical conservatories in Manhattan, such as Julliard. She was that good!

New Patterns

Then one day at age 16 a new pattern began to emerge. There were nights when she would not come home until late. She began to change and gravitate to what I called and discussed with her as "the lowest common denominator" of life on the streets. And New York can be a very dangerous place, especially for a young teen who was trying to find herself. The signs continued to show when we moved to a larger, more comfortable apartment nearer to her high school. I thought this would make her happier, as she could avail herself of the many after-school options at this training ground for fine musicians, but that never happened. Over time I began to read the signs. She was not doing well in school and things were not as they seemed. She was getting up late, coming home late, and never talked about her class work, which I pushed her to do. Eventually the trumpet was abandoned and she showed signs of confusion while distancing herself from me.

One day it happened: She ran away. I found out from one of my sisters that Holliday had made her way to my sister's house in Vermont; having had such a strong tie with her grandmother (my mom), it wasn't surprising that she went back there. Perhaps this was some adolescent crisis that would pass with some time in a more familiar and safe environment. That wasn't the case. Within two days she had what we would call a "pre-psychotic break" and was rushed back to a residential treatment facility, where she spent nine months outside of New York City in treatment for what was diagnosed as bi-polar disease.

Every weekend I took three trains to visit her in the hospital which was renown as the best adolescent mental health treatment facility in the U.S. and which looked more

like a gorgeous country club than a lock-up for the insane. She got stable, regained her sweetness and sense of humor, and eventually was placed in a group facility back in Manhattan with many open privileges. She got herself employment and took classes to get her GED. At last, I thought, she was going to be fine. But, I had no idea what was really brewing behind the smiling façade and apparent compliance with the rules at the group home. I went there weekly to meet with her and the clinical staff, all in attempts to normalize her to medications that would maintain her for life, establish a path back to finishing school, and perhaps restarting the trumpet, though it was clear that a career in music was not her destiny.

Changing Plans

I took a job in California at the urging of the residential clinical staff and with Holliday's permission, ready to escape the years of disappointment with her situation in NYC and ready to pursue greater horizons for my own career. I had the great fortune of being selected to run the first teacher training project in HIV prevention at ETR Associates, funded totally by the Centers for Disease Control and Prevention (CDC) as a showcase program. I loved it. I co-wrote four major training programs and began to travel and deliver them around the country. Meanwhile, I was in close contact with Holliday and her caregivers.

I was shocked one day, two months after my arrival in Santa Cruz, CA., to get a crisis call that Holliday had gone AWOL and had spiked a manic episode. She was in the emergency area of Bellevue hospital, along with a roomful of homeless persons and victims of violent street crimes. Was this MY daughter? My mother and sister flew to NYC and rescued her. I flew in shortly after and discussions began to unfold about her need for further care. Two more manic episodes later it was crystal clear that NYC without me wasn't working and that a new plan had to be made. The residence in NYC was not the answer, but perhaps living with my parents and attending day treatment in Vermont would be the cure.

One month later, as plans were being made for her transfer to Vermont, my mother dropped dead from a heart attack and the family experienced a major earthquake. Holliday was not going to Vermont, after all. After my mother's funeral and witnessing my father's weak state, I arranged for Holliday to be discharged to live in Santa Cruz near me. I had a tiny studio apartment at that time, but knew we could find her suitable housing. Soon after she landed on my doorstep, I moved to a larger apartment to accommodate this new paradigm. It wasn't long before she stopped taking her bipolar medications. Weeks later, another major manic phase occurred.

When she was manic, she was classical: grandiose, free spending with money, sexually irresponsible, and out of control. I could handle the depressive phases of her personality, although that was never pleasant, but the mania changed her into someone else, a personality that I abhorred. It took about a nanosecond to realize that living with me, bringing home strangers she met at bars, and not working or doing much of anything wasn't going to work for me.

Bingo, Infected

Holliday went on a road trip with one of her cronies and I was fortunately able to focus on my wonderful new job and dig into its demands. One day, I was sitting at my desk preparing for the first round of trainings, when a man's voice (an Army Medical Director) unexpectedly left a message on the phone, urging me to contact him about my daughter's health status. Did I know that she was trying to get into the U.S. Army? And did I know she was being rejected because she was HIV-positive? What?

Here I was, a national leader designing trainings and writing the first teacher training manual for HIV prevention and my own daughter has turned up HIV+. Impossible. There must be some mistake. But there wasn't. It seemed that during that phase in NYC before her "break" and the trip to Vermont, she had had unprotected sex with a young man in her GED program (whom the teacher had warned me was "not a good influence on Holliday") and who happened to be an IV drug user. Bingo. Infected.

This was the beginning of the long journey with HIV/AIDS. By the time she was assessed in the local clinics, her HIV had become full AIDS. She was to live many years with herpes, skin disorders, never-caught PCP, and to be on the edge of being diagnosed with some other opportunistic infection many times. Life was never going to be the same again.

THE JOURNEY OF HIV

Holliday had a journey that few young women her age may have endured. At times I had to show my own capacity for "tough love" and draw the healthy boundaries about what I would and wouldn't accept—bringing home strangers into our apartment, running astray, not working, spending months at a time in deep depressive limbo while not taking the anti-bipolar nor the HIV drugs. These patterns went on for the many years of the term of her disease.

Ups

In the early 90's I moved back to the east coast. This big step for me, was in part made possible by her progress in finding a wonderful support system, two steadfast AIDS buddies who remained a part of her life to the end, the Santa Cruz AIDS Project, friends, and a newfound spiritual path of Buddhist chanting that really gave her life a new blush of hope and community.

At that time, her housing was good, her health remained intact, and she was even well enough for one of the few periods in the course of her HIV/AIDS to hold a job as a full-time temporary postal worker, her all-time favorite career. There she was, in uniform, driving around the hills and valleys of beachside Santa Cruz county in a white-painted USPS jeep-like vehicle and living with her horrible secret of AIDS. I remember our joking about the terms they used (like "going postal!") and how happy being a part of the postal team made her feel. That, too, was short-lived.

Around that time, she met the love of her live which was perhaps the best thing that ever happened in her life. That man (whom we'll call Sam) became her partner, she got pregnant through unprotected sex which never infected him, and they were married in the midst of a huge crowd of thrilled and rather surprised friends. The news of her pregnancy sent chills up my spine, when I feared that could cause such a strain on Holliday's physical health that she might die.

When the announcement of her pregnancy hit home, members of a support group that I had joined helped me realize the positives about the new drug protocols. Holliday got involved in an experimental, landmark San Francisco peri-natal program and thrived. Her baby was born HIV negative and healthy. Our miracle baby! I was instantly in love with her, of course. Grandmothers bond with their grandchildren, just as Holliday did with my mom. I was so pleased to see such a good marriage that was so compatible, and watched Holliday become a great mother. Things were working well for them except for constant economic challenges, for which I helped as much as I could.

The pull to be with my daughter and grandchild deepened and I wanted to be closer to them, so I moved from Manhattan to San Francisco. Suddenly though, much to my great chagrin, Sam's mother wanted them to live near her in Florida. I gave them my blessings and managed to visit them and their adorable infant-toddler. I saw that Holliday seemed to be doing the best in her whole life, working in a spa resort with her husband, taking her AIDS medications, feeling happy, and being a great mother.

But problems began to emerge. There was rather poor health care for HIV/AIDS in that region, and their financial struggles grew. After two years, I convinced them to move back to California.

And Downs

After a couple of months her husband found a good job, but I noticed that Holliday was waning. A *madow* can read the signs: her health was not good even though she was a client of AIDS Project of Los Angeles, and I could sense her struggle in being a full-time mom. Perhaps more importantly, her mental health was on the slide. She seemed so unhappy in the tiny, disheveled house, which was a 50-minute ride from mine. She'd call me up and cry, "Mom, I feel so isolated, and it's so hard, taking care of the little one. I miss you, can I come over?" The answer was always "Sure, honey, whatever you need." But I began to doubt that things were going to get better. Something inside of me told me, "Keep a good lookout, Patti, things are getting worse."

One day, she called me, and in a quiet voice, filled with tentativeness and shock, she said, "Mom, I have some news. I think you're not going to like it…Sam got a new job." She paused…"It's in Santa Cruz and we're leaving next week." Then she sobbed. I couldn't stop him. He was determined to move back to an area where he felt he could thrive. He knew that things weren't good with Holliday where they lived. So he took a good job, and I rallied to their support once more.

The truth? This was the beginning of the dive downward. The financial pressures persisted, and they moved in with friends to what I can only say was an unhealthy hovel. I was appalled and scared for Holliday's mental and physical health. Quickly, Holliday's health declined. A few months later, when I could make it up there, I learned that she had gone off all of her HIV-related medications. There she was, lying in bed for hours, letting her little girl be babysat by a television screen, in a house that was bad for her health, with the demands of motherhood taking their toll and not much hope of change in sight. Sam, God bless him, did his best, struggling with many hours of hard work and trying to be a good dad and husband. Finally, after she had a total emotional breakdown during one of my visits and then attempted suicide by slashing her wrists in a hospital parking lot, she got into mental health treatment. And she got back on a chemical soup of anti-depressants, mood stabilizers, and of course, more drug cocktails to treat the HIV/AIDS.

She did get better and was more optimistic. From a distance, I attempted to help her get back into community college, where she had been a part-time student years before. Her voice changed and got faster, and her words were grandiose. I had to wonder if this was the new meds or if it was the return of the loathsome mania.

The Last Straw

Her manic symptoms worsened, and after a rapid escalation, one day she simply left home. To me this was full mania, once again, running the show and destroying everything in its path. It was also the combination of drugs that tipped the scales. Days later and thousands of dollars of debt, she somehow managed to find strangers, all men, to take her in. Until the final curtain she lived with a man whom I've never met, but who helped her survive. She never returned home to be

a mother again. I knew she was getting sicker when she began avoiding her daughter. I decided to help her husband get his divorce so he could escape the enormous debts she had created. Despite having joint custody, Holliday just couldn't handle having her child around. She cried on the phone telling me she couldn't control her, the house was too chaotic, and she didn't have the energy.

Holliday always told me, during those horrible two years of being absent from her child and me, that she was taking her medications from the AIDS project there. I wondered. In the summer of 2003 we visited her daughter together in Santa Cruz, thinking that if I were there she might reconnect and find the strength to be with an active five-year-old who longed to be with her mommy. But, I noticed that Holliday was not tracking conversations very well and that she had a visible and hideously ugly molluscum growth over her eye, which troubled me. She seemed weak, disconnected, and very unhappy. I assumed it was because of her living far away and feeling guilty about not seeing her daughter, and I began to work hard to encourage her to consider using her Social Security income and Medicaid options to move back to Santa Cruz to be nearer to her daughter and friends. She never took action, even when I pleaded and recited lists of action steps to what seemed like deaf ears.

A MOTHER'S TALE TO THE END

That is Holliday's story. Now it's my turn. The story is not yet over. This is what happened to me as a result of Holliday's decline and demise due to HIV/AIDS and bipolar disease—along with an inadequate, reluctant, and resistant medical system, and a world that doesn't fully acknowledge or address the real range of needs of people living with HIV/AIDS or what their families require to make it through.

June 10, 2004. She visits me in LA. She is not right. She is out of touch, standing and staring with a vacant gaze; she's making strange sounds, is hardly speaking, and looks terribly thin. We go up to the country and a gay friend (who is all too familiar HIV/AIDS) notices something is not right.

Later June, 2004. I begin to push her to get assessed at her AIDS program in Northern California, and to get on new meds. She admits to me, in a teary talk, that she hasn't been taking any medications for months. She is declining.

July, 2004. She goes to Santa Cruz to get into services, with both Santa Cruz AIDS Project and county health department services, both reputedly good projects for PWAs. She lives with an older couple who try to get her into proper care and back on track.

August 12, 2004. I drive up to see her with the plan to help her get new housing, arriving late and staying at my son-in-law's house. Fatigued and anxious, I arrive at the home of our friends to see Holliday. When I open the door I nearly fall down: I see a wizened, weak, and ill person sitting hollow-cheeked on the couch, with a horrid smell of death on her breath, "Who is this?" I nearly burst into tears and am in shock when I realize it's Holliday, who is very ill, dehydrated, wasted, and confused; they tell me she's been silent, not taking in fluids or food and lately has had bouts of sudden diarrhea. The next day I take her to emergency care where I then try to get her into a hospital/nursing facility; they say she's technically not sick enough. The caregivers insist on asking the patient, someone who cannot decide anything, what she wants. She can hardly stand up or speak.

August 12–17, 2004. I push the system; I try everything I can think of to make someone help us. I meet with social workers, public health nurses, medical doctors, and Santa Cruz AIDS Project staff, who alone are going to get her into an independent living home in town. I still feel she needs more supervised care and the county social worker balks at my insisting on this. I get her a mental health assessment but they cannot serve her. We have one final MD appointment at which time I cry out to the doctor, "Don't you see what I am seeing? I think she's dying. She is not going to make it." He is moved enough to test her mental faculties while I leave the room. When I return he whispers to me, "Patti, she has AIDS dementia." Finally, someone else sees what I see. A possible *madow* knows.

What can be done? They tell me, "Well, she can be in an Independent Care Facility and if things get worse, then she can get into more intensive care. Of course, she'll have to make her own meals." I think to myself, "Make her own meals? She cannot even track how to get herself a glass of water. She stands for hours gazing into space in one place. She's NOT going to make it that way."

I am told that I must wait for two weeks for her room to be ready. Our friends cannot keep her. I decide, with the loving support of my own partner, Robert, that I have no choice other than to bring her home with me to wait it out. She's given bottles of anti-depressants and threatened that if she doesn't curb the depression she'll never be compliant with the AIDS medications that are next. In our drive down to Los Angeles, she is barely able to drink, eat, or keep a focus. In her stupor, she manages to swallow the pills for me.

August 17–27, 2004. We return to LA and then drive up to the country home, where she can have a lovely room to herself with us in the next room and be nurtured by the beauty of nature in the summer. I notice she's waning, that she's failing. I try everything in my power to get her to

drink and eat; I try to get her to take anti-depressants. She tries. She is dying. She cannot drink, she cannot eat, she cannot sleep. The severity of her waning and confusion, along with not taking in anything to eat or drink, begins to frighten us. We take her to the local hospital emergency room. I am crying. It's her birthday, must we? A doctor tells us she's dehydrated, then judgmentally and coldly quips, "Why didn't they force her to take HIV medications? That's her problem. Here, get these pills and make her take them," handing me a prescription note I cannot see from the blur of my tears welling up in my eyes. Don't they see what a possible *madow* sees? We get her the medications and for two days she tries to force them down her dry throat, drinking two ounces of water and barely swallowing ¼ cup of soft food a day. This can't continue. She's going to die right here in our living room.

The Sunday before Labor Day Weekend, 2004. I have a video project meeting at in my house. I can't believe it's happening this way. She stays with Robert. Oddly enough, they are watching Emmy nominated comedy shows in his living room and guessing at the winners, all of whom she has picked correctly. That comedian self is still alive. At 5 pm he calls over to me and says, "It's time. We have to take her to emergency. Patti, we can't keep doing this. I think she's dying." Her lips are cracked and bloody, she's breathing with difficulty, eyes glazed over, and she hasn't drunk or eaten or taken any pills today. She must go with us. We drive back to the ER in our country town and I pray for a miracle. I pray for a doctor who sees what I see. We wait, then we are given unspeakable privileges by a divine power, with nursing staff who are incarnate angels. They arrange for tubal feeding and hydration for her while we wait, and then we meet her, the doctor we've been hoping for. "You are right," she says, "You can't handle this. She needs to be in a hospital. Let's see what I can do." After five hours in the ER lounge, they dismiss us to go home for rest. All that night I lie awake in bed, poised for the phone to ring while she tests Holliday to find a reason to admit her to hospital care. "It's spinal meningitis, Patti, but not the contagious kind. I can send her to a fine hospital down the hill. You can see her in about four hours there." I am so relieved. Finally, she is going to be helped.

The next day. We arrive only to wait some more. A young man introduces himself as our intern and begins asking a thousand questions, while my mind is spinning, longing to see her. She's lying on a gurney in the hall outside her room, with bags on bags on a pole and tubes in her like roadmaps. I have to keep my hand in motion to sign all the paperwork, especially to get control of decisions now. Words like advanced directives, living wills, power of attorney, all become a familiar part of my new vocabulary.

She recognizes Robert and me with a half-baked smile, and we begin the hospital visitations—11 days running, with two hour, one-way drives and five to eight hour visits in her room, and never once does she not know it's us. But oh, does she seem psychotic. She says things to me like, "Why are you floating over my head, mom?" or "Watch out, there are huge green lizards crawling up the walls." And there is always, always, the paranoia, "They want me out of here. I have to get out of here. I think they need this bed, I've got to go." That is to become her final mental state for the duration: constant fear and anxiety. It is so painful to watch; it makes me weep in silence. She won't drink or eat, so she remains on tubes to hydrate, feed, and take in the drugs.

Of course, being modern medicine, she is forced to take the AIDS medications. Always with the goal of a cure, these heroic measures bother me and her. I have horror-like memories of her pulling out her feeding tubes, of wrist restraints, of fighting with the night staff to take her off the tubing, of an unending battleground for her survival. The doctors with decision-making powers have Asian names and I never meet them. The social workers with their phones always on hold try to help, but their failed attempts are never enough. The lovely and warm nursing care staff provides the only solace I feel at the hospital.

I'll never forget the day I hit my wall. It is the third day and I've had it: no word from any MD yet. Finally, I corner the young intern, the only contact I'm allowed, and I say to him, pinning his body against the wall outside her room beside the 24-hour nursing police stationed there to make sure Holliday doesn't pull the plug, "Doctor, I need an answer today. I cannot wait another day. Neither can she. I need to know. Should we proceed with placing her in hospice?" His breath stops, he pauses, he makes a cellular call, and dashes down the hall. Minutes later he finds me to initiate the process. I weep a sigh of relief when he agrees with this almost-*madow's* prognosis. She is not going to make it out of here cured.

Labor Day Weekend, 2004. The medical team has changed and I have a smart new female resident, who's calling all the shots. At first, after the hospice diagnosis is made, they seem reasonable about the paper chase to get her into the hospice I have found and that I insist on for her placement, the Carl Bean House in LA, ten minutes from our city home. But Western medicine is governed by bed counts and curing patients. Now that the Do Not Resuscitate and the "do not administer any more medications" orders are in place, the pressures on me mount to get her out of there. I hate it. No social workers can resolve the paper needs; the doctor keeps pressuring me to get her out of the bed and into her choice of nursing home for the final ride. I resist and fight them all

tooth and nail. They all fear she might die this weekend while we all wait for paperwork to determine her destiny, and keep up the constant phone calls pressuring me to let them send her away.

Tuesday, after Labor Day, 2004. Finally, I get through the bureaucracy and the word is "GO"—she's getting out of the hospital. The endless wait is over. My baby's going to the hospice to die.

The last 16 days in Carl Bean House. Now there are questions about if she can make the two-hour ambulance trip. She does. When I can get in, hours later, there are big black wrought iron gates in front of the hospice that remind me of the gates to heaven. I wince as they screech open for my visitation: heavy, dark, sinister, yet inevitably welcoming. It's destiny.

My sister, her youngest aunt, visits. We laugh and smile. I see Holliday light up, with intermittent clarity. She complies with eating and drinking without forcing—the care is stupendous. These are the living angels, those caregivers. No pushing, no heroic measures, no making anyone live. This hospice is about letting someone die—with grace, dignity, and comfort. Palleative care. What a gentle term. It's the only way to die—no more tubes; let her enjoy the last weeks or months.

It's ups and downs. At first it's ups; for ten days she seems better. Robert and I visit her every day, taking her in the wheelchair out to the atrium to watch the fish in the aquarium. The other patients are like seeing a concentration camp studies, but the care and love by the staff are always there, palpable, and the beauty of the place is healing. Holliday is increasingly paranoid, "Hey, mom," she whispers to me one day, "I have to get out of this bed now. I just heard them, they need the bed." Her crazy mind saddens me but she always knows Robert and me. One time, in the beginning of her stay there, one of the staff asks, "Is this your husband?" pointing to my partner Robert. She grins the most luminous grin, "No," she laughs in a half-conscious way. We then laugh as a team about her "husband, Robert" and it's part of the sweetness we all get to share for her time there.

Most of the time it's lucidity on vacation. Our friend, the nurse, is always there as a peaceful presence and all the staff are present to answer any question, including the Big Question: Will you know when she is about to die? The answer to that is yes, and I am floored that most normal people are not told the big secret, that the nurses know the bodily signs and symptoms of death—the change in breathing, the change in body temperature and blood pressure. The final performance of the human journey is calculated in signs. It's the final weekend. Robert and I notice that things have changed. And, the huge moloscum over her left eye has now closed the eye, which almost makes me throw up with grieving, and now it's spreading to the right one. If she lives much longer she'll be blind. I don't know if I can bear that turn.

A few days before she dies. I write this in my journal: *38 days and X hours later I calculate the length on my watch. I watch over her, Mother Bird over her chick caught in the barbed wire nest and failing fast. Time feels so precious and fleeting. I try to edit my new manuscript, but my thinking's a sieve with bats in the belfry. A million butterflies take flight in my skull, all on a wind heading her way. I can't focus. I can't think of anything but my Little Bird. How many hours are left? How many hours do I have to clutch a delicate swinging hand or plant loving kisses on a sunken sallow cheek or speak "I'm sorry's" and "I love you's" or yet another chorus-full of assurances to pack in her bags before the long train ride somewhere. Somewhere beyond. Somewhere unknowable. Somewhere where I hope angels play hopscotch and she can grow gossamer wings. Somewhere to be held in another mother's arms, one who waits at the gates for her e-ticket to heaven. How many hours are left? How can I shift the attention away from her—this vortex running on empty—and reboot my life towards me? I can't now. I count the days of a deathwatch. Was Nurse Dee on target or another false alarm today? How do we keep vigil on the dying and plant an arrow on the bullseye for the moment called Death?*

I linger naked on the couch, shuddering at the thought of seeing her again, trembling with worry I won't stay composed, startled at the rapid decline. My black kitty feels my angst. He lies in a catwad, paws turned under, whiskers flared, nostrils open and eyes half-watching me. Waiting for me to return. Me. To return from the vortex. How many more hours?

The Monday after the weekend. But turn she does. She becomes listless, takes no more tastes or bites of the melon that Robert has convinced her to nibble on for him. No more drinks of the Ensure to keep her energized. No more getting out of that bed.

The day before she dies, something miraculous happens. Up until this point her mental state is so fragile and unclear that she hasn't been told she is going to die. Would that matter? Doesn't the self know? A *madow* wonders. A chaplain visits with her, along with his little fluffy dog, props her head up so that she can turn with her good eye to see him and they talk about death. They talk about how she is so loved by her mother and Robert, so much that the hospice talks about us all the time as the single most loving couple they've ever seen visit here at the hospice each day. And he tells her that the end is near, while his soothing voice and beaming smile comforts and guides her. I know in my soul that he is the instrument that allows her to begin to let go of her wracked body and let death take her to her peace.

Thursday, September 23, 2004, 8:47 AM. "Patti, it's Margo, from Carl Bean. Her deep wise voice trails off, "I think you

LESSONS LEARNED

1. That the pain for a mother is to not be able to fix it for their child (We can't always "make the boo-boo go away").
2. That a mother knows when her child is dying.
3. That we as the *madows* must learn to accept, let them go, and live our own lives to the best we can.
4. That we must do something to right the wrongs of losing a child to HIV/AIDS, or any other preventable disease.
5. That dying is a graceful and holy process.
6. That to be the angel at the side of a child that you birth and that you death is an honor and a blessed event.
7. That death is not to be feared; it's suffering we fear.
8. That death is not final; there are memories that carry the person into the future even without a body.
9. That it takes courage, great strength, and conviction to fight against a bureaucratic system that is not geared toward letting patients die.
10. That dying is not failure. It is inevitable and often it IS the only option.
11. That dying from this horrible disease may be the pathway for peace.
12. That being fully present, relinquishing control, accepting the process of her dying whatever form it may take, is the pathway to our own salvation as *madows*.
13. That we the *madows* must speak up and speak out. We must tell the world what is like to watch a young, able-bodied, and able-minded adult wither, become mentally deranged, and to behold their wretched diseased body. That we the *madows* must help as a united voice to stop the spread of HIV, a fully preventable disease. And if we cannot stop its spread through prevention, we must scream loudly to advocate for our children's necessary care, including ample social and mental health care services, especially for people who suffer the dual burden of both HIV/ADIS and a mental health condition as my daughter did.
14. That with both full AIDS and an incurable bipolar condition (that in the end joined forces to kill my own daughter Holliday), we must have more openness and acceptance of the scourge these diseases bring forth.
15. Finally, as a sexologist it is my duty to report that it was sex that brought her into this life and sex that took her out. Please, don't become a *madow* if you don't need to. I sense that this was part of my own evolution and personal journey, but it's not an easy path to walk. Be careful with sex. Be sexually responsible: use safer sex and stay away from drugs. If you can save the life of your own child, regardless of his/her age right now, you will never have to share my enormous grief.

need to come." It's "the call," the one every mother on the planet dreads receiving. The day she dies, the big wrought iron gates at Carl Bean House are being repaired and do not open. At 2:20 pm she is gone.

THE TALE CONTINUES, AFTER

The next day I wrote in my journal.

> *I am sobbing oceans, torrents, tsunamis of saltwater, gut-wrenched tears. Bobbing on a huge sea of so much sorrow, I plunge, into the breakers, drowning, will I ever come up? On top of the ocean and ride-a-wave, the crashes against the shore, picking up, shaking it off, talking some more to caring, loving friends and family who never can know this grief the way I spit it back out like a baleen expiration. Grief. Will it ever stop? Twenty years of sorrow—grief—waiting—of sludge now pouring out like water through a sieve of a life ended too soon. A mother's sorrow too huge, too heavy, too deep to pass over lightly. I feel so many urges—to cry, to run away, to hide, to shout, to claw at the air like those flailing tiny bones-for-arms she conducted with in her hospital beds. Will Holliday show up, a broken spirit or as a whole angel, to say, "It's okay, Mom. I'm here. It's true. It's not really over but the struggle…" I hope so. I miss her. I cherish those Little Bird handholds that measured the past two weeks in hospice care. I miss having such a huge to-do at the top of my daily list. I miss her half-eyes-open glances and half-made smiles. This was my child. She was my only baby, my own, from my flesh and blood and bone. Now a cement slab is her home. "Welcome home, angel, Mommy's here."*

The next night I pray for a sign from her.

> *I set up the shrine I now make portable to carry images and artifacts from the closet in tow where I set it up right after her death. An altar to my child, a respectful corner to honor her, her life. I found photos, though few, of the last few years and sprinkled them like diamonds across my dresser, parked like toy cars in front of photos of my gurus looking down at her. I pack up all the photos and beautiful albums and insert the Earth geodes a friend brought to her in hospice as a reminder*

of her origins. I hold her watch and glasses, clotted with the DNA of her living body that she shed each day. The three dead red roses from the small plant that graced her hospice room the entire 16 days until they both died that Thursday, gave her and me something to see for its beauty. Now, me, lying in bed without her here, in the ethers, in the unknown, among the missing, I anchor myself in hope. I read aloud from a friend's book on Goddesses and find solace. I'm calming, centering, peace is on its way, at least for an instant. I pray that she'll reveal herself to me. That night an angel appears, sprinkles her fairy dust on my fingers that I have placed into the air, sensing a presence, and giving me the "knowing" that life doesn't end. She was there. She visited me that night. I fall asleep for a while.

After a few days pass, I write my awareness.

Everyone dies. No one says the D word. We need to have a map. We deserve to know how it all ends, don't we? I ache with a lesser pain today. Maybe it was from going to my country house where she last slept before the hospital care and feeling that contact with her spirit. There is no pain left, just peace now. I am back to the present again. I tune into women in the café where I write, grateful for the beauty all around me—the grand fountain wakes up gushing and whooshing its soothing sparkling waters. The sound feels so comforting and a flash of panic grabs me by the throat, worried maybe I'll think of it as great cascades of tears, like mine gone quiet now.

MY INVITATION TO YOU

After Holliday's death I was overwhelmed by the outpouring of love, care, and support from literally hundreds of friends and a rejoining of my estranged siblings. That was the best gift of all. We all enjoyed a beautiful memorial service, and oddly enough, she had more people present for her funeral than it seemed for her life. She was deeply loved and adored by many, especially her Buddhist friends, her family, and my circle of dear friends who knew her and me over the many years. This memorial was a real testament to her wonderful spirit, her gentle way in the world, her humor, and her miracle of having such a beautiful daughter who is vibrant, bright, pretty, healthy and alive, and living happily with her dad in Santa Cruz in the home I helped him buy.

Without the expression of care, love, and support for me and my family, my *madow* recovery process wouldn't have been possible. Without a caring life partner by my side, this journey would have been far more agonizing. For that I am eternally grateful to Robert. Along with that, the expressing of all of the deep feelings along the way is part of how we as *madows* cope: feeling our way back into the light; honoring the dark spots and times are part of the journey we walk. We must let ourselves feel the loss, feel the grief, and move on. It is in the moving on, reconnecting with the power of life itself, perhaps, and doing something about this hideous disease and its ripple effects that lets me go on.

I hope you will join me in honoring the women with AIDS who have died, their mothers, and helping me to advocate for a world in which we all learn to cope.

AFTERTHOUGHTS

I don't regret the amazing experiences that this journey has given me—some of which make me a better person, a wiser soul, and a more giving being. I hope my story helps you and yours.

At Holliday's memorial service, I read a quote from her birthday gift to me a couple of years ago, a little golden book called "Love Is a Beautiful Thing." On one of the ornate pages is written a quote from Henry David Thoreau: "Do what you love; know your own bone; gnaw at it, bury it, unearth it and gnaw it still."

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SIECUS Report readers are invited to tell her their stories as AIDS madows or the stories of those they know. Write to PO Box 411, Lake Arrowhead, CA 92352-0411 or askthesexcoach@aol.com.

UNDERSTANDING HUMAN PAPILLOMAVIRUS AND CERVICAL CANCER

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"You can get so confused
that you'll start in to race
down long wiggled roads at a break-necking pace
and grind on for miles across wierdish wild space…"

—Dr. Seuss

Indeed, charting a course through the HPV maze can be confusing. Once fairly obscure, genital Human Papillomavirus (HPV) has become much more widely known—if not completely understood. It has been at the heart of political and scientific research and debate and a source of media attention.

Human Papillomavirus is a nearly universal STI that most sexually active Americans are thought to contract at some point, though most are never diagnosed clinically. At any one time, about 20 million people are infected with HPV although most will have no visible symptoms and are unaware that they are infected. The increased awareness of HPV is driven largely by new diagnostic methods (such as HPV DNA testing), the prospects of prophylactic vaccines looming on the near horizon, and its role in sexual health politics.

HPV—THE BASICS

Genital HPV is one of the most common sexually transmitted infections (STIs) in the United States. About 6.2 million people get genital HPV each year. It is estimated that about 80% of sexually active people have been infected with HPV at some point in their lives.

HPV is a group of DNA viruses that infect the skin. There are well over 100 different types, many of which are associated with benign lesions such as common warts of the hands and feet. About 30 HPV types are associated with anogenital skin and sexual transmission—of these, some are "low-risk" HPV types that can cause lesions such as genital warts, which are usually harmless. Of greater concern are the "high-risk" types that can lead to abnormal cell changes (most often detected of the cervix). Most HPV infections resolve spontaneously and generally do not lead to health complications.

Prevention, Diagnosis, and Treatment

Outside of sexual abstinence, the surest way to prevent HPV (and other STIs) is to refrain from sexual contact with an infected person or to be in a long-term mutually monogamous relationship with an uninfected person. Although condoms may not provide complete protection, multiple studies have shown that using condoms consistently and correctly can reduce the risk of HPV-related diseases such as genital warts and precancerous and cancerous changes to the cervix.

Because HPV is so widespread, prevention is particularly challenging. The most promising prevention method would, of course, be a vaccine. Groundbreaking research indicates the stunning potential these vaccines have as public health interventions—recent data from a large phase III trial shows Merck's Gardasil vaccine is 100% effective at preventing high-grade cervical diseases associated with the oncogenic HPV types found with about 70% of cervical cancers. Vaccines to prevent HPV are expected to be available within the next year. Young people ages 8-17 are presumed to be the target recipients of these vaccines. The initial indication of HPV vaccines will almost certainly be to prevent infection in females, which means the target population will be young girls who are not yet sexually active.

Until the FDA approves a vaccine, the age of immunizations will not be known. However, immunization for young girls prior to sexual activity and "catch up" vaccines for older populations are likely to be recommended. An effective strategy to ensure wide coverage would be for states to make vaccines mandatory for children at some school entry point.

The most common diagnostic methods for HPV involve visual exams, Pap tests, and HPV DNA tests. Pap tests can detect abnormal cell changes in the cervix, but cannot directly diagnose HPV. Specialized DNA tests can diagnose HPV in the cervix. These tests are routinely used to clarify abnormal Pap test results. They are also approved for primary screening in women over 30, in combination with conventional Pap testing. Regular screening through

Pap and HPV DNA tests can catch cervical cancer in its early stages, when there are no symptoms. Since cervical cancer typically takes years to develop, with regular screening, nearly all cases can be prevented or cured.

Genital warts (which do not cause cancer) can now be treated with patient applied topical therapies, as well as through conventional clinic-based approaches—these include health care provider-applied chemicals and outpatient surgical options like cryotherapy (freezing with liquid nitrogen), scalpel excision, electrocautery (burning), and in some cases laser surgery. The choice of therapy varies depending on the size, location, and number of warts.

The Cervical Cancer Link

The immune system of most healthy people is able to suppress HPV within a few months. In some cases, though, these cell changes persist over many years and if left undetected can eventually progress to cervical cancer. Although most HPV infections do not lead to cancer, about 99% of cervical cancer tissue contains high-risk HPV.

It is not clear why some cases fail to clear naturally and progress along the continuum to cancer. However, co-factors linked with cervical cancer include smoking or exposure to second-hand smoke, having intercourse at an early age, and long-term use of oral contraceptives.

Cervical cancer develops slowly, often taking ten years or more, and is seldom detected in women who have regular Pap screening (either alone or in combination with HPV DNA tests). Mortality related to this disease is especially tragic considering that it is virtually always preventable through screening at consistent intervals. According to the American Cancer Society, the number of cervical cancer deaths in the U.S. has dropped 74% since the advent of Pap screening in 1955—there are now approximately 10,000 cases of cervical cancer in the U.S. each year, and nearly 4,000 deaths as a result. Yet cervical cancer is preventable, treatable, and curable.

The burden of cervical cancer is now experienced most keenly in countries lacking screening programs. The World Health Organization (WHO) estimates approximately 80% of global cervical cancer deaths occur among women in developing nations. WHO estimates that there are more than 500,000 cases of cervical cancer worldwide annually and nearly 300,000 deaths, making it the second-leading cause of death from cancer among women globally.

Psychosocial Impact

The psychosocial impact of HPV can be devastating. HPV can cause emotional anguish that many newly diagnosed women find overwhelming. Research by Ellen Daly, Ph.D. and Kay Perrin, Ph.D. found that 94% of infected women felt the need to hide the fact that they had HPV. More than 75% of women diagnosed with HPV reported feelings of anxiety and blamed themselves for the diagnosis, as if they were "paying" for past sexual behaviors. Similarly, a survey of health care providers conducted by the Centers for Disease Control and Prevention (CDC) found patients commonly react with fear and anger upon diagnosis.

CDC is conducting additional studies in this area. Initial data from surveys of women recently diagnosed with HPV reveal that many are concerned about the source of HPV transmission, lack of support and communication with partners, and potential damage the diagnosis may have on relationships. Interestingly, women are more affected when HPV is viewed as an STI than as a precursor to cervical cancer.

HPV and Men

As confusing and unfamiliar as the subject of HPV is for women, it's even more difficult to find information for men. Not a great deal is known about the "natural history" of the virus in males. Diagnostic options are essentially limited to a visual inspection to detect lesions (warts or cell changes)—there is no direct test for the virus itself currently approved for clinical use with men. Health issues with HPV occur even less often with males than females, but "high-risk" HPV types are associated with some penile and anal cancers, the latter of which raises discussions on the need for anal screening for men who have sex with men (and women with a history of anal sex). This is often elusive, though, as many health care providers and laboratory staff are unfamiliar with means of anal cytology sampling and specimen interpretation.

HPV AND POLITICS

Given the ubiquitous nature of the infection and the need for awareness of both the potentially harmful outcomes of the virus and the importance of screening to prevent them, one might assume HPV discussions would be a straightforward, apolitical addition to the public health agenda in the U.S. and around the world. Things are seldom that simple where matters pertaining to sex are concerned, and HPV is drawing attention both from groups touting an abstinence-only approach to prevention as well as those who promote comprehensive sexual education programs. It is sometimes difficult to separate the intertwined, often ideological, messages surrounding HPV, condoms, and abstinence.

HPV found its way into the forefront of political debate in 2001. A provision inserted into the Fiscal Year 2001 Labor, Health and Human Services, and Education (Labor-HHS) appropriations bill by former Representative Tom Coburn (R-OK), now a U.S. senator, fueled a political debate around HPV and condoms. The provision required the CDC to conduct research projects and a series of public education efforts to better inform providers and the general

public about HPV. It also required the Food and Drug Administration (FDA) to reexamine condom labels to determine whether they are medically accurate with respect to condoms' "effectiveness or lack of effectiveness" in preventing HPV.

It isn't currently known exactly how effective condoms are at blocking HPV transmission. The virus isn't likely to penetrate condoms made of latex; however, because HPV can exist on skin that condoms don't cover, protected sex is not a guarantee that transmission won't occur. Some legislators are urging the FDA to alter current condom labeling to specifically state these limitations. However, listing limitations could discourage rather than encourage condom use. Those who are concerned about STI prevention see this as a major problem—condoms are currently the best product available to prevent STIs.

This equation may soon be made even more complex. Preliminary data presented by researchers from the University of Washington in Seattle offer evidence that consistent, correct condom use does reduce risk (perhaps as much as 70%) of HPV acquisition. This will likely come to a head soon, as the FDA recently issued revised condom labeling for public comment.

Like condoms, the potential for an HPV vaccine is becoming the center of controversy. Beyond the normal concerns found with any new childhood vaccine (such as worries that kids are becoming little "pincushions"), HPV vaccines have the added element of offering protection against a virus acquired through sexual activity—this juxtaposition of children and STIs is a potentially volatile combination that many find unnerving.

There is concern, for example, among some abstinence-only proponents that HPV vaccines may lead to a false sense of security that will ultimately encourage promiscuity and lead to risky sexual behavior among youth. Others, however, counter that these vaccines will be of incalculable value in preventing cervical cancer and reducing the medical and psychosocial burdens associated with a diagnosis of HPV-related diseases, and should be universally implemented.

The pharmaceutical companies with vaccines in clinical trials, Merck and GlaxoSmithKline, are keenly aware of these controversies and, like many advocates of a comprehensive approach to STI prevention and sexual education, are trying to "normalize" discussions by focusing strongly on women's health and cervical cancer prevention components, and less on a sexually transmitted virus as the causative factor.

FDA approval for the first vaccine is anticipated early in 2006. National and state organizations have begun to prepare for the myriad social and access issues that the vaccines may raise. In the midst of potential controversy, maintaining the central public health goal of preventing cervical cancer will be essential.

LOOKING FORWARD

HPV presents multi-faceted challenges, impacting individuals on many levels. As vaccines come to market and new diagnostic technologies inevitably gain wider use, these issues are likely to receive even greater scrutiny. Resources that give clear, consistent information are of paramount importance as increasing numbers of patients, partners, and health care providers become aware of HPV and ask questions.

This is evident in the comments made by one newly diagnosed woman who wrote to HPVnet, a service operated by the American Social Health Association that responds to more than 3,000 emails about HPV each year: "I am 19 years old and so scared out of my mind, I can't put it all into perspective. Maybe you can tell me something that will make sense to me and help me better understand what I may be facing with HPV." Clearly, she's not alone.

EMERGENCY CONTRACEPTION: THE SCIENCE AND POLITICS DRIVING THE DEBATE

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Emergency Contraception (EC) refers to any type of birth control method used after intercourse to prevent pregnancy. The two possible methods are the emergency insertion of an Intrauterine Device (IUD) or the administration of emergency contraception pills. Emergency insertion of an IUD is rare in the United States, and, therefore, the scientific and political debates in the U.S. center only around the use of emergency contraceptive pills, sometimes referred to as the "morning after pill." For the purpose of this article EC will refer solely to these pills.

EC is a high dose of regular birth control pills that can be taken within 120 hours (five days) of unprotected intercourse as a back up method of birth control if a woman did not use a regular method or if her regular method failed (e.g. the condom broke). When taken within 72 hours of unprotected intercourse, EC can reduce a woman's chance of becoming pregnant by 80 to 85 %. It is most effective if taken within the first 12 to 24 hours of unprotected sex.[1] EC does not protect against sexually transmitted diseases, including HIV.

EC has been the subject of heated debate in the United States for several decades. Unfortunately, conservative far right organizations have made this debate not about women's health but about abortion, sexual activity, and the restriction of healthcare choices for women. Three issues remain at the center of this debate: 1) whether EC is an abortifacient; 2) whether this back-up method of birth control discourages the use of regular methods of birth control; and 3) whether emergency contraception increases sexual activity. This article is designed to explore these issues and provide some political and historical context to the debate around emergency contraception.

HISTORY OF EMERGENCY CONTRACEPTION

The practice of using oral birth control pills after unprotected sex has been in place since the 1960s. The first such documented case was published in the mid-1960s when physicians in the Netherlands administered postcoital estrogen to prevent pregnancy in the victim of a sexual assault.[2] In 1984, the United Kingdom became the first country to approve a product specifically packaged as EC and today, dedicated products are registered in over 80 countries worldwide.[3]

Beginning in the 1970s, physicians in the United States prescribed a similar method through "off-label" use of oral birth control pills, a common and legal practice.[4] Nonetheless, official approval by the Food and Drug Administration (FDA) was still decades off.

Advocates and physicians wanted the regimen to be formally approved by the FDA so that there would be the possibility of greater access and increased awareness among women. This process began in November 1994 when the Center for Reproductive Rights, formerly known as the Center for Reproductive Law and Policy, attempted to force the FDA's hand, and filed a citizen petition with the FDA on behalf of a coalition of leading medical and public health groups. The petition requested that the FDA require manufacturers of birth control pills to include information about EC in the product packaging of certain brands.[5] Although the FDA declined the petition and, in doing so, declined to require the relabeling of these products as emergency contraception, the agency took an unusual step and unanimously declared, in June 1996, that emergency contraceptive pills are a safe and effective way to prevent pregnancy if taken in the recommended dosages up to 72 hours after unprotected intercourse.

FDA Approval

Shortly thereafter, in February 1997, the FDA officially declared regimens of commonly used oral birth control pills as safe and effective for use as emergency contraception to prevent pregnancy. The FDA published dosage information for six brands of oral contraception in an effort to "encourage manufacturers to make this additional contraceptive option available." The FDA stated that it would accept applications to manufacture and market EC without requiring new drug trials as the safety and efficacy of EC had already been demonstrated.[6] It noted that "…similar regimens have been used extensively in the United States in the last two decades, even though no products are approved and labeled for this use."[7] Given these circumstances, it is no wonder that, in certain circles, emergency contraception was for years known as "the nation's best-kept secret."

Manufacturers took the FDA up on its offer and in September 1998, the FDA approved an application from Gynetics, Inc. to market the Preven Emergency Contraception Kit, the first official emergency contraception

regimen in the United States. The Preven Kit contained the Yuzpe regimen of emergency contraception pills, named for Canadian physician Albert Yuzpe who, in 1974, published early studies demonstrating the safety and efficacy of EC.[9] Though Preven is no longer being manufactured, limited supplies still exist and are still considered safe and effective.

Less than a year later, in July 1999, the FDA approved a second EC product, Plan B, which contains only one hormone, the progestin levonorgestrel. A World Health Organization-supported study found this to be more effective and have fewer side effects than the earlier approved regimen.

Over-the-Counter Status

The FDA approval of Preven and Plan B was hailed by advocates and doctors alike, yet many felt that EC should be even more widely available through over-the-counter (OTC) pharmacy access. Women in 37 countries, including Albania, Belgium, Canada, Denmark, Israel, Morocco, Portugal, South Africa, Sweden, and the United Kingdom can obtain EC without a prescription.[10] However, the campaign for OTC status in the United States has been slowed by anti-choice and anti-family planning organizations that have launched misinformation campaigns about the safety and efficacy of EC.

In February 2001, the Center for Reproductive Rights filed a petition with the FDA on behalf of more than 70 medical, public health, and other organizations, including SIECUS, to grant over-the-counter status for EC. No decision was ever issued for this petition.[11] Efforts continued in April 2003 when the Women's Capital Corporation, the former producer of Plan B (which has since been acquired by Barr Laboratories), submitted an application to the FDA to switch Plan B from prescription-only to OTC status. The first decision in a string of many to be made on this application was handed down in December 2003 when a joint FDA advisory panel comprised of the Reproductive Health Drugs and Nonprescription Drugs Advisory Committees voted overwhelmingly, 23-4, in favor of making EC available over the counter, without a prescription.

POLITICS TAKES OVER

Despite this overwhelming support for granting over-the-counter status, the issue remains unresolved almost two years later. These past two years have been characterized by misinformation campaigns, stall tactics, and political maneuvers.

Misinformation Campaigns

The most common misconception about EC is that this method of birth control is an abortifacient—a method of abortion. Although many people view emergency contraception and medical abortion as similar, in reality EC only works to *prevent* pregnancy and does not terminate a pregnancy. Anti-choice organizations continue to mislead the

EC LEGISLATION AND OTHER ISSUES

Pharmacy Access

While the FDA continues to drag its feet on this much-delayed decision, several states have taken decisive action concerning the sale of EC.

- As of August 2005, seven states—Alaska, California, Hawaii, Maine, New Hampshire, New Mexico, and Washington—allow pharmacists to dispense emergency contraception without a physician's prescription under certain conditions.[1]
- In August 2005, Illinois mandated that all pharmacies that carry contraceptives must fill prescriptions for birth control pills, including emergency contraception (EC), just as they would any prescription, for anyone with a valid prescription.

Federal Legislation

While advocates and policymakers continue to wait for the FDA's final decision, federal legislators have introduced several bills in Congress seeking to raise awareness and increase access to EC.

- *The Emergency Contraception Education Act (HR 3326)* would provide $10 million for the development and dissemination of information on EC to the public and to health care providers.
- *The Compassionate Assistance for Rape Emergencies Act (HR 2928, S 1264)* would require emergency rooms in all federally funded hospitals to promptly provide EC to women in cases of sexual assault.
- Both of these bills are also included in the *Prevention First Act (HR 1709, S 20)* which includes equity in insurance coverage of prescription contraception, a mandate for medically accurate information on contraception, and a call to establish or expand teenage pregnancy prevention programs.
- Another bill *(HR 2635)* would require emergency contraception to be available at all military health care treatment facilities.

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public and argue that EC causes an abortion despite the fact that this is in direct contradiction to the scientific literature and opinions of mainstream health organizations.

According to generally accepted definitions of pregnancy, put forth by public health entities such as the American College of Obstetricians and Gynecologists, the National Institutes of Health, and the U.S. Department of Health and Human Services, pregnancy begins when a pre-embryo completes implantation into the lining of the uterus.[12] Originally there was some ambiguity as to how exactly EC prevented pregnancy—it was unclear whether it suppressed ovulation thereby preventing fertilization or whether it worked after fertilization by preventing a fertilized egg from implanting in the uterus. Recent studies, however, prove that EC works only by interfering with ovulation, thus preventing fertilization.[13] [See Population Council article on p. 20] In fact, there is no evidence that EC prevents implantation, alters sperm or egg transport, inhibits fertilization, or changes cervical mucous.

Attempts to prevent the granting of OTC status to EC have also focused on whether EC decreases use of regular birth control methods or increases sexual activity, especially among adolescents.

In January 2004, 49 members of Congress, led by anti-choice and anti-family planning advocate Representative Dave Weldon (R-FL), sent a letter to President Bush expressing concern with adolescent use of EC and charging that the FDA panel did not consider the impact that over-the-counter availability may have on the sexual health of young people. The letter stated that, "we are very concerned that no data is available to suggest what impact this decision will have on the sexual behavior of adolescents and the subsequent impact on adolescent sexual health. We are concerned that adolescent exposure to sexually transmitted infection will increase because of the availability of [Plan B] over-the-counter. This availability may ultimately result in significant increases in cancer, infertility and HIV/AIDS."[14]

In reality, the FDA panel had considered over 15,000 pages of data from approximately 40 studies showing that making Plan B available over the counter was safe and effective for all women of reproductive age. In particular, the application included the results of eight behavioral studies, whose sample sizes ranged from 160 to 1,000 women ages 15-45. These eight studies compared women who had been provided with EC regimen in advance of needing it with others who had been provided only information on this method of pregnancy prevention. They found that women who receive EC in advance are more likely to use the regimen but are not more likely to engage in unprotected sex. In addition, the studies found that these women were not more likely to be inconsistent in their use of regular contraceptives, including condoms, than women who were given only information. In fact, a three-year study of more than 20,000 women ages 16-49, found that over-the-counter availability of EC does not lead women to rely on it instead of other birth control methods.

Further, to the contrary of politicians' rhetoric that the availability of EC would lead to increased sexual activity among young women, the same study released in the *British Journal of Medicine*, also found that access to EC does not lead to an increase in unprotected sex. The researchers concluded that fears that non-prescription EC would alter contraceptive and sexual practices were unfounded. The report noted that, "making emergency contraception available over the counter does not seem to have led to an increase in its use, to an increase in unprotected sex, or to a decrease in the use of more reliable methods of contraception."[15] The authors concluded that, "given the apparent absence of negative consequences, and the fact that many women clearly prefer to buy [emergency contraception] over the counter, our study supports the case for lifting the ban on over-the-counter sales in the United States and other countries."[16]

Based on this research, the FDA panel was unanimous in finding that the drug was safe for use without a prescription and that there was no evidence to suggest that over-the-counter availability would lead to substitution of EC for regular use of other contraception methods. A recurring theme in the panel's discussion was that over-the-counter status of EC would increase timely access to this back-up birth control method for both adult women and teenagers, which in turn would yield significant individual and public health benefits.[17]

Stall Tactics

In February 2004, one week before the scheduled date to make its decision of whether to grant over-the-counter status to Plan B, the FDA announced that it would need an additional 90 days to complete its review of Plan B's application. While not specifically referencing the Weldon letter, the FDA stated that the 90-day extension would permit the agency to more thoroughly review the data on use by adolescents.[18] Then in early May 2004, the FDA overruled the recommendation of its own advisory panel and issued a "non-approvable" letter to Barr Laboratories, officially rejecting its application. The FDA stated that it rejected Barr's application based "primarily on the lack of data concerning OTC use of the product among adolescents younger than 16 years old. The sponsor's application contained no data in subjects under 14 years of age and very limited data in adolescents 14 to 16 years old."[19]

Steve Glason, acting director of the FDA's Center for Drug Evaluation and Research, acknowledged that the decision to reject Barr's application was far from typical but stated that he was worried that if young women had easier access to EC, some may be more likely to have sex without condoms, thereby exposing themselves to an increased risk

for sexually transmitted diseases.[20] The FDA's decision was all the more unusual as evaluation of drug safety for use over-the-counter generally looks to be sure that: 1) the benefits outweigh the risks; 2) the potential for misuse and abuse is low; 3) the consumer can use it for self-diagnosed conditions; 4) it can be adequately labeled; and 5) health practitioners are not needed for the safe and effective use of the product. In keeping with this criteria, the joint advisory panel overwhelmingly found that all evaluation measures had been successfully been met.[21]

In its "non-approvable" letter to Barr Laboratories, the FDA suggested two possible options for Barr to obtain approval for marketing Plan B over the counter: 1) submitting additional data demonstrating that the drug can be used safely by women under 16 years of age without professional supervision; or 2) supplying additional information in support of a revised "dual label," which would allow the marketing of Plan B as a prescription-only product for women under the age of 16 and an over-the-counter product for women 16 and older.[22] In July 2004, Barr Laboratories submitted a response to the FDA proposing that Plan B be marketed with the "dual label" status.

In January 2005, the FDA announced that it was delaying its decision on Plan B once again simply indicating to Barr Laboratories that it would complete the review of its application in the coming months. This was in contradiction to the *Prescription Drug User Fee Act* which demands that the FDA make decisions on applications within ten months of the original application's submission and within six months of an amended application.[23]

In March 2005, during a Senate Health, Education, and Labor Committee (HELP) hearing, Senators Patty Murray (D-WA) and Hillary Rodham Clinton (D-NY) pressed the then-Acting Commissioner of the FDA, Lester Crawford, to answer questions about Barr Laboratories's long-pending application for nationwide over-the-counter approval of Plan B. Crawford promised during the hearing that the FDA would decide on the application "within weeks."[24] To help keep the pressure on the FDA, the two Senators placed a hold on Crawford's nomination—in effect blocking a full Senate vote on his nomination to the position of FDA Commissioner until the FDA made a decision on Barr Laboratories' application. Although Crawford had promised a decision within weeks, it was not until July 15, 2005, that Secretary of Health and Human Services, Michael Leavitt, announced that the FDA would make a decision by September 1, 2005 whether to allow the sale of EC over the counter, without a prescription for women ages 16 and older.[25] With this announcement, Senators Murray and Clinton lifted their holds on Crawford and cleared the way for the Senate to vote on his nomination as head of the FDA. On July 18th the Senate approved Crawford as FDA Commissioner, 78-16.[26]

Political Maneuvers

Despite these promises by Crawford and Leavitt, Crawford announced on August 26, 2005 that the decision would be further delayed. He explained that the agency had concerns over whether or not a product could be sold both OTC and with a prescription in the same packaging and issued an Advance Notice of Proposed Rulemaking (ANPR) to request comment on whether the FDA has the authority to approve a drug in both prescription and OTC form and whether such a limitation would be enforceable.

Five days later, on August 31, Susan F. Wood, Director of the Office of Women's Health and Assistant Commissioner for Women's Health at the FDA, resigned in protest of this decision.[27] Wood explained that this latest decision to delay the ruling was not made in the usual manner of the FDA, but instead "at the commissioner level…where most if not all of the professional staff were excluded."[28] In her remarks to colleagues upon her resignation, Wood stated that the FDA had never previously raised questions regarding teens' use of other drugs. "I have spent the last 15 years working to ensure that science informs good health-policy decisions," Wood said. "I can no longer serve as staff when scientific and clinical evidence, fully evaluated and recommended by the professional staff here, has been overruled," she concluded.[29]

Wood's resignation was an unparalleled public show of dissension for the FDA. The media attention the resignation garnered prompted additional moves from lawmakers. Many supporters of the Plan B application for OTC status, including Senators Clinton and Murray, accused Crawford of making a political decision that ignored science and public health. "It is time for the FDA to stop playing games with the health and well-being of millions of American women," the Senators said in a joint statement. "Day by day, the public's confidence in the FDA's ability to make decisions based on scientific evidence of safety and efficacy is eroding."[30]

Senators Clinton and Murray called on Senator Michael Enzi (R-WY), the chairman of the Senate Committee on Health, Education, Labor and Pensions, to hold a hearing on the latest delay.[31] A spokesman for Senator Enzi stated that he is considering their request for a hearing, and has separately asked the FDA to explain how and why it reached this latest decision.[32] Senators Murray and Clinton have also asked the Government Accountability Office (GAO) to finally release its report on the FDA handling of Plan B, a report requested by them last summer. "This is not game over, this is game on," Murray said, adding she was not about to give up.[33] In a separate letter, four House Democrats asked President Bush to issue "a clear directive" to federal agencies that all health-related decisions are to be based on science.[34]

In a surprise move, Commissioner Crawford resigned on September 23, 2005 just two months after his confirmation.[35] During Senate hearings on the Fiscal Year 2006

EMERGENCY CONTRACEPTION'S MODE OF ACTION CLARIFIED

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Emergency contraceptive pills, a hormonal treatment that can prevent pregnancy if taken within 72 hours of unprotected intercourse, have been the subject of heated debate. At issue is the method's mechanism of action: does it prevent the meeting of egg and sperm, or does it prevent a fertilized egg from implanting in the uterus? Recent research by members of the Population Council's International Committee for Contraception Research (ICCR) and other scientists shows that the most popular method of emergency contraception appears to work by interfering with ovulation, thus preventing fertilization, and not by disrupting events that occur after fertilization.

The most common and effective form of emergency contraception contains levonorgestrel, a progestin. It is sold in the United States and Canada under the name Plan B®. Reproductive physiologist Horacio B. Croxatto of the Chilean Institute for Reproductive Medicine in Santiago, Chile, and his colleagues studied the effects of levonorgestrel on the reproductive cycle of female rats, monkeys, and humans. Croxatto and one of his study partners, biomedical researcher Vivian Brache of PROFAMILIA in Santo Domingo, Dominican Republic, are members of the ICCR.

Emergency Contraception in Animal Studies

Croxatto and his colleagues exposed female rats to very high doses of levonorgestrel at various stages in their reproductive cycle, either before or after ovulation or before or after mating. "When a woman uses emergency contraception," Croxatto explained, "she does not know whether she is taking the pills before or after ovulation or before or after fertilization." The researchers found that levonorgestrel inhibited ovulation totally or partially, depending on the timing of treatment and the dose administered. However, the drug had no effect on fertilization or implantation when it was administered shortly before or after mating or before implantation.

Next, Croxatto and his colleagues studied the effects of levonorgestrel given to *Cebus* monkeys either before ovulation or postcoitally. The reproductive cycle of each animal was monitored by ultrasound examination of the ovaries, vaginal smears, and measurements of blood hormone levels, in order to time the administration of levonorgestrel. The researchers found that, when given before ovulation, levonorgestrel was able to inhibit or postpone ovulation. Alternatively, when it was given after mating—at a time when fertilization was believed to have occurred (on the basis of previous monitoring)—the pregnancy rates observed were identical in cycles treated with levonorgestrel or with a placebo. This indicates that levonorgestrel did not interfere with any postfertilization process required for embryo implantation.

Emergency Contraception in Women

Women may become pregnant when they have intercourse in the five days before ovulation. This is because sperm can live in the female reproductive system for up to five days. An egg, however, is usually viable for only six to 12 hours after it is released. Croxatto, Brache, and their colleagues studied the effects of levonorgestrel administered during this fertile preovulatory period of women's menstrual cycle.

Twenty-nine women in Santiago and 29 women in Santo Domingo were enrolled in the study. All of the women were protected from pregnancy by tubal ligation or a nonhormonal intrauterine device. The study was randomized, double-blind, and placebo-controlled: the gold standard for clinical trials. Women were treated with either placebo, a full dose of Plan B emergency contraception, or a half dose of the drug. They were followed over several cycles and, by the end of the study, each woman had received all three of these treatments, separated by resting cycles. The women were randomly assigned to receive the treatments at specific times during the fertile preovulatory period, according to the diameter of the leading ovarian follicle, as determined by ultrasound. The leading ovarian follicle is the structure that ruptures to release the mature egg.

In 82 percent of Plan B–treated cycles, follicles failed to rupture within the five-day period following treatment (the maximum time span sperm would survive in the female reproductive tract), or there was some significant ovulatory dysfunction. These conditions occurred in only 41 percent of placebo cycles. The rate of ovulatory dysfunction observed with Plan B treatment is identical with the estimated efficacy rate of Plan B emergency contraception. Blood tests indicated that Plan B affects ovulation by suppressing the surge of luteinizing hormone (LH) that normally acts as a trigger for the ovulatory process.

"There is no doubt that fertilization would not have taken place in those women should they have had intercourse prior to treatment," says Croxatto. "We conclude that the effects exerted by Plan B, when it is taken before the onset of the LH

surge, may fully explain the pregnancies averted by emergency contraception. Failure to affect the LH surge, because treatment was begun too late in the fertile preovulatory period, explains the 20 percent failure rate of this method."

Resource

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Agriculture Appropriations bill, Senators Murray and Clinton issued a statement about the FDA and Crawford's leadership on the Senate floor stating that, "with the resignation of Dr. Crawford, the FDA has a real opportunity to restore its battered reputation and nominate a leader with vision and drive to ensure that the FDA upholds its gold standard of drug regulation." The senators succeeded in persuading colleagues to include language in the agency's final appropriations bill expressing congressional concern over the direction of the FDA and calling for an expedited decision on Plan B.[36]

THE NEED REMAINS

Currently, half of all pregnancies in the United States (about 3 million) are unintended, and approximately 1.3 million of these end in abortion. According to the labeling approved by the FDA itself, Plan B decreases the risk of unintended pregnancy resulting from contraceptive failure or unprotected intercourse by 89%. It is estimated that access to EC could reduce unintended pregnancies by at least 50% among American women.[37] In fact, use of EC alone prevented an estimated 51,000 abortions in 2000, suggesting that increased use of EC may have accounted for up to 43% of the total decline in abortion rates (11%) from 1994 to 2000.[38] Widespread availability of emergency contraception has the potential to reduce many of these unintended pregnancies, and dramatically reduce abortion rates in the United States.

For too many years, politics has been allowed to dictate a debate that should have been easily settled by the well-documented and unassailable scientific evidence that shows that emergency contraception is safe, effective, and desperately need. It is time for the FDA to see through the misinformation and political tactics and to allow women unfettered access to this important method of preventing unintended pregnancies.

Resources

Emergency Contraception Hotline, 1-888-NOT-2-LATE
Emergency Contraception Website, www.not-2-late.org

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SUBJECT TO DEBATE: VIRGINITY OR DEATH!

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Imagine a vaccine that would protect women from a serious gynecological cancer. Wouldn't that be great? Well, both Merck and GlaxoSmithKline recently announced that they have conducted successful trials of vaccines that protect against the human papilloma virus. HPV is not only an incredibly widespread sexually transmitted infection but is responsible for at least 70 percent of cases of cervical cancer, which is diagnosed in 10,000 American women a year and kills 4,000. Wonderful, you are probably thinking, all we need to do is vaccinate girls (and boys too for good measure) before they become sexually active, around puberty, and HPV—and, in thirty or forty years, seven in ten cases of cervical cancer—goes poof. Not so fast: We're living in God's country now. The Christian right doesn't like the sound of this vaccine at all. "Giving the HPV vaccine to young women could be potentially harmful," Bridget Maher of the Family Research Council told the British magazine *New Scientist,* "because they may see it as a license to engage in premarital sex." Raise your hand if you think that what is keeping girls virgins now is the threat of getting cervical cancer when they are 60 from a disease they've probably never heard of.

I remember when people rolled their eyeballs if you suggested that opposition to abortion was less about "life" than about sex, especially sex for women. You have to admit that thesis is looking pretty solid these days. No matter what the consequences of sex—pregnancy, disease, death—abstinence for singles is the only answer. Just as it's better for gays to get AIDS than use condoms, it's better for a woman to get cancer than have sex before marriage. It's honor killing on the installment plan.

Christian conservatives have a special reason to be less than thrilled about the HPV vaccine. Although not as famous as chlamydia or herpes, HPV has the distinction of not being preventable by condoms. It's Exhibit A in those gory high school slide shows that try to scare kids away from sex, and it is also useful for undermining the case for rubbers generally—why bother when you could get HPV anyway? In 2000, Congressman (now Senator) Tom Coburn of Oklahoma, who used to give gruesome lectures on HPV for young Congressional aides, even used HPV to propose warning labels on condoms. With HPV potentially eliminated, the antisex brigade will lose a card it has regarded as a trump unless it can persuade parents that vaccinating their daughters will turn them into tramps, and that sex today is worse than cancer tomorrow. According to *New Scientist,* 80 percent of parents want the vaccine for their daughters—but their priests and pastors haven't worked them over yet.

What is it with these right-wing Christians? Faced with a choice between sex and death, they choose death every time. No sex ed or contraception for teens, no sex for the unwed, no condoms for gays, no abortion for anyone—even for that poor 13-year-old pregnant girl in a group home in Florida. I would really like to hear the persuasive argument that this middle-schooler with no home and no family would have been better off giving birth against her will, and that the State of Florida, which totally failed to keep her safe, should have been allowed, against its own laws, to compel this child to bear a child. She was too young to have sex, too young to know her own mind about abortion—but not too young to be forced onto the delivery table for one of the most painful experiences human beings endure, in which the risk of death for her was three times as great as in abortion. Ah, Christian compassion! Christian sadism, more likely. It was the courts that showed humanity when they let the girl terminate her pregnancy.

As they flex their political muscle, right-wing Christians increasingly reveal their condescending view of women as moral children who need to be kept in line sexually by fear. That's why antichoicers will never answer the call of prochoicers to join them in reducing abortions by making birth control more widely available: They want it to be *less* available. Their real interest goes way beyond protecting fetuses—it's in keeping sex tied to reproduction to keep women in their place. If preventing abortion was what they cared about, they'd be giving birth control and emergency contraception away on street corners instead of supporting pharmacists who refuse to fill prescriptions and hospitals that don't tell rape victims about the existence of EC. David Hager (see Ayelish McGarvey's stunning exposé, and keep in mind that unlike godless me she is a churchgoing evangelical Christian) would never use his position with the FDA to impose his personal views of sexual morality on women in crisis. Instead of blocking nonprescription status for emergency contraception on the specious grounds that it will encourage teen promiscuity, he would take note of the six

studies, three including teens, that show no relation between sexual activity and access to EC. He would be calling the loudest for Plan B to be stocked with the toothpaste in every drugstore in the land. How sexist is denial of Plan B? Antichoicers may pooh-pooh the effectiveness of condoms, but they aren't calling to restrict their sale in order to keep boys chaste.

While the FDA dithers, the case against selling EC over the counter weakens by the day. Besides the now exploded argument that it will let teens run wild, opponents argue that it prevents implantation of a fertilized egg—which would make it an "abortifacient" if you believe that pregnancy begins when sperm and egg unite. However, new research by the Population Council shows that EC doesn't work by blocking implantation; it only prevents ovulation. True, it's not possible to say it never blocks implantation, James Trussell, director of the Office of Population Research at Princeton, told me, and to antichoice hard-liners once in a thousand times is enough. But then, many things can block implantation, including breast-feeding. Are the reverends going to come out for formula-feeding now?

"It all comes down to the evils of sex," says Trussell. "That's an ideological position impervious to empirical evidence."

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VULVODYNIA: A HIDDEN WOMEN'S HEALTH ISSUE

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Vulvodynia, or chronic vulvar pain, is a common problem affecting women. Historically, cases of vulvodynia with no apparent physical explanation were seen as resulting from psychosexual factors. However, we now understand that vulvodynia is a chronic pain disorder that typically leads to problems in many areas of functioning, including sexual and psychological functioning.

In 2004, the International Society for the Study of Vulvovaginal Disease (ISSVD) defined vulvodynia as vulvar pain or discomfort, usually described as burning, that cannot be attributed to any physical problem such as inflammation or infection.[1] The ISSVD further designated two categories of vulvodynia, depending on the location of the pain. Localized vulvodynia refers to pain in a particular part of the vulvar area, such as the vestibule, whereas generalized vulvodynia refers to pain affecting the whole vulvar region. Each category is further divided according to the situation that elicits the pain: provoked (i.e., the pain is elicited by physical contact), unprovoked (i.e., the pain occurs independently of external stimulation, otherwise known as spontaneous pain), and mixed (i.e., the pain occurs in both provoked and unprovoked situations). Provoked pain can result from sexual activities (e.g., penile-vaginal intercourse), leading to pain during sexual intercourse—otherwise known as dyspareunia; it can also result from non-sexual activities (e.g., tampon insertion, gynecological examinations, sporting activities), or it can occur in response to both kinds of situations.

This paper will focus on the two most common types of vulvodynia, *vulvar vestibulitis syndrome* (VVS) and *generalized vulvodynia* (GVD). VVS refers to pain localized to the vulvar vestibule (i.e., the entrance of the vagina) in response to physical contact[2], and GVD describes spontaneously occurring vulvar pain affecting the entire vulvar area. When the term *vulvodynia* is used, it refers to all types of chronic vulvar pain in general. [3]

Recent epidemiological studies indicate that vulvodynia affects approximately 16% of women in the population; VVS affects 12% of pre-menopausal women, and GVD affects 6-7% of women, a large proportion of whom are over the age of 30.[4] Despite this prevalence, many women have never heard of vulvodynia and many health care providers and counselors lack the information they need to explain, diagnose, and treat this problem.

VULVAR VESTIBULITIS SYNDROME

VVS is believed to be the most common cause of dyspareunia in women of child-bearing age.

How is VVS diagnosed?

The most common complaint of a woman with VVS is that of dyspareunia. Many women, however, will not report this during a routine examination, and it is crucial that providers specifically ask about pain during intercourse. The pain should be carefully characterized in terms of location (e.g., at the entrance of the vagina versus the pelvic area), description (e.g., burning versus itching), and temporal pattern (e.g., provoked or unprovoked). Asking questions such as these will serve to both validate the pain experience of the patient and aid in diagnosis. In addition, these questions may allow for the classification of VVS as either primary (i.e., the pain has been present since the first intercourse attempt) or secondary (i.e., the pain developed after a period of pain-free intercourse). Clinical studies suggest that an equal number of women have primary and secondary forms of VVS.[5]

As we know, many women have limited knowledge of their vulvar anatomy; a diagram is often helpful in localizing the pain and assessing its patterns during particular activities. Providers should also ask questions about past treatments, previous diagnoses, and remedies that have helped or exacerbated the pain, as these are key in obtaining a complete picture of the problem. Furthermore, careful questioning about how the pain has affected the patient's relationships, sexual functioning, psychological well-being, and overall quality of life will provide a more thorough understanding of the pain and clarify potential treatment options.[6]

During the physical examination, it is important to search for potential causes for the pain (e.g., infections, dermatological conditions, sexually transmitted diseases). If potential factors are found, they must be treated; however, the pain may remain. The standard gynecological tool for diagnosing VVS is the cotton-swab test, which consists of the palpation of various areas of the vulvar region with a cotton-swab.[7] If the patient reports pain when pressure is applied to the vestibule, then the diagnosis of VVS is made. The cotton-swab test is usually performed in a clockwise manner around the vestibule. Research has shown that pain

ratings increase with each successive palpation[8]; therefore, clinicians should consider a randomized order of cotton-swab palpation to avoid sensitization of the vulvar vestibule and to avoid causing unnecessary pain to the patient. There are also devices, such as the vulvalgesiometer, that allow for the application of known pressures, which can be useful in a research context.[9]

What causes VVS?

There is no simple answer regarding what causes VVS, although numerous theories have been proposed.[10] One of the most consistently reported findings associated with the onset of VVS is a history of repeated yeast infections.[11] It is not clear, however, whether the yeast itself, the treatments undertaken to remedy the infections, or a combination of both is responsible.[12] It is clear that unnecessary treatment for yeast can aggravate the problem, and it is important that both women and health care professionals understand that treatment should not be undertaken without confirmation of an existing infection.[13]

A second theory posits that altered tissue properties in the vestibule may play a role in the development and/or maintenance of VVS by rendering it more sensitive to stimulation. Research has found that the vestibular tissue of women with VVS has increased inflammatory mediators[14] (although this has been debated[15]), increased nerve fibre innervations[16], increased pain receptors[17], increased blood flow[18], and increased pain-related peptides.[19] These changes could lead to a heightened sensitivity in response to vestibular pressure, as has been shown in recent studies[20], which is consistent with the clinical picture of provoked pain in VVS. Taking a cotton-swab and touching different areas of the vestibule in a non-affected woman is perceivable but not typically painful; however, this same stimulation in the vestibule of a woman with VVS is perceived as highly painful and distressing.

Factors outside the vulvar vestibule have also been suggested as playing a role in VVS. Women with VVS have been found to exhibit an increase in pelvic floor muscle tension[21], possibly representing a protective reaction against, or a conditioned response to, vulvar pain. It is not clear, however, whether the tension leads to the pain, or results from the pain. Other studies examining sensitivity outside the vulvar vestibule have reported that women with VVS are more sensitive to stimulation in general: they are more sensitive to touch, pain, pressure, manual palpation, and heat pain in areas such as the deltoid muscle and forearm[22] and report more non-vulvar pain complaints[23] than non-affected women. These results are consistent with several studies of chronic pain patients, such as those with chronic headache[24], migraine[25], temporomandibular disorder[26], and fibromyalgia[27], in which heightened sensitivity outside the area of primary complaint has been documented. Further supporting the generalized nature of the pain of VVS are findings from a recent brain imaging study, indicating that women with VVS process sensory information in an augmented fashion, as do patients with other pain conditions causing hypersensitivity.[28] These results reveal that a more generalized pain process, involving both local and central nervous system (i.e., the brain and spinal cord) mechanisms, may be involved in the initiation and maintenance of VVS.

One potential explanation for this increase in general sensitivity in women with VVS is that of genetic involvement.[29] Recent studies have found that women with VVS have a genetic profile associated with a severe and prolonged pro-inflammatory immune response. Based on these findings, the authors proposed that, in some women with VVS, there is a genetic susceptibility for the development of a chronic localized inflammation in the vestibule after an initial inflammatory response has been triggered (e.g., after yeast infections). The prolonged and intensified inflammation could then trigger other events that may result in increased pain sensitivity due to chronic inflammation in both genital and non-genital areas of the body.

Hormonal factors could also have systemic effects. Studies have shown that women who used oral contraceptives at a young age have an increased risk of developing VVS later in life.[30] Early menarche and dysmenorrhea were also associated with increased risk.[31] These findings suggest that genetic and hormonal factors may play a role in VVS, but the question of *how* remains to be answered.

Other theories point to psychosocial (i.e., non-physical) factors such as distress, anxiety, depression, low sexual self-esteem, harm avoidance, somatization, shyness, hypervigilance, and pain catastrophization,[32] which have also been found in women with VVS. It is not clear whether these factors predate or develop after the pain; regardless, it is important to investigate the role of these factors in the maintenance of the pain since they may effect pain perception.[33]

It is surprising that despite the significant impact of VVS on sexual functioning, the examination of relationship factors has been limited. Seventy-four percent of women with VVS report that the pain impacts their relationships[34] although they do not typically report significant levels of couple distress. In addition, high relationship adjustment is related to decreased pain severity in women with dyspareunia.[35] Relationship distress is associated with psychosocial attributions for the pain, suggesting a possible interaction between pain coping style and relationship adjustment.[36] In terms of negative relationships involving sexual abuse, many studies comparing women with VVS to non-affected women show no differences in the prevalence of sexual abuse[37]; however, a recent epidemiological study linked vulvodynia with experiences of childhood violence.[38]

How can VVS be treated?

Regardless of the cause of VVS, many areas of these women's lives must be addressed in order to achieve therapeutic success. These areas include pain as well as any muscular, psychological, sexual, psychosocial, and relationship issues. Potential treatment options include medical interventions, pelvic floor biofeedback and physical therapy, and cognitive-behavioral therapies.

Medical Interventions

Medical treatments targeting the vulvar vestibule consist of several options, such as topical, injectable, systemic, and surgical interventions. Topical interventions, such as the application of lidocaine and corticosteroid creams, have led to some success in a subset of women with VVS, but overall, the data are not convincing. Whereas a recent study found that long-term lidocaine ointment application decreased pain scores and re-established sexual activity in a group of VVS sufferers[39], a more rigorous placebo-controlled study of the effectiveness of cromolyn (antihistamine) cream[40] did not reveal any evidence of effectiveness. Other research has shown that the application of capsaicin (the active ingredient in hot peppers) to reduce the response of pain receptors in the vulvar vestibule region led to partial relief in women with VVS.[41] Given both the severe burning experienced shortly after capsaicin application (despite pre-treatment with anesthetic cream) and the long-term nature of this treatment, the authors suggested that this treatment be used as a last resort.

Injections of interferon[42], lidocaine in combination with methylprednisone[43], and botulinum toxin[44] were also found to be of some value in small studies. Systemic medications for treating VVS, although an option, have not been thoroughly investigated in the empirical literature. One recently published randomized trial revealed that oral antifungal medication was ineffective for treating VVS.[45]

Long-term follow-up data and randomized clinical trials are needed to fully assess the effects of these topical, injectable, and systemic medical treatments, as there is some concern that they may cause more harm than benefit.[46] Unfortunately, there is no empirical evidence for the success of any oral medication, such as anti-depressants, for the pain of VVS; however, there is some evidence that low-dose antidepressant medication can be an effective treatment for the pain of GVD (see below).

Surgical intervention has also been proposed for the treatment of VVS. Surgical removal of the vestibule (vestibulectomy) has been the most investigated treatment for VVS to date with more than 20 published outcome studies, yielding success rates ranging from 43-100%, with most of the rates typically surpassing 65-70%.[47] This procedure involves the removal of the sensitive tissue of the vestibule. It is a minor surgical procedure, preformed as a day surgery under general or spinal anesthesia, and consists of the excision of the hymen and of the vestibule surrounding the vaginal opening. There are many variations of the surgery[48], with some involving mobilization of the vaginal mucosa to cover the excised area. Following this procedure, women are generally instructed to abstain from all forms of vaginal penetration for 6 to 8 weeks. Because of its invasive nature and because it does not result in 100% success, many health professionals recommend the surgery only after other less invasive treatment options fail.

Pelvic Floor Biofeedback and Physical Therapy

VVS has been associated with an increase in pelvic floor muscle tension.[49] Targeting the pelvic floor musculature through pelvic floor biofeedback and physical therapy in an effort to reduce this tension has been found useful for the treatment of VVS. In pelvic floor biofeedback training, patients use a vaginal sensor and a monitor that provide a direct measure of their muscle tension. This can be used to promote muscle training with respect to contraction, relaxation, and the acquisition of voluntary control. After approximately four months of biofeedback training, it was reported that vulvar pain decreased and sexual functioning increased in women with VVS.[50]

Physical therapy often combines a biofeedback component with soft tissue mobilization and other techniques. The effectiveness of this approach has recently been evaluated in a retrospective study of VVS.[51] Results indicated that after an average of seven sessions, physical therapy yielded moderate to great improvement in over 70% of participants. Treatment resulted in significant pain reduction during sexual intercourse and gynecological examinations, and led to improvements in intercourse frequency and levels of sexual desire and arousal. These findings indicate that physical therapy is indeed a promising treatment for women who suffer from VVS, although prospective studies are needed.

Cognitive-Behavioral Interventions

Cognitive-behavioral treatments for VVS include cognitive-behavioral pain management and sex therapy to reduce pain and restore sexual functioning. Success rates ranging from 43-86% have been reported in two uncontrolled studies in which sex therapy and pain management were combined.[52] A prospective and partially randomized treatment outcome study investigating the effectiveness of behavioral intervention with or without surgery[53] indicated that women in both groups reported decreases in pain; there were no significant differences between women who had undergone the behavioral intervention alone versus those who underwent the behavioral intervention combined with surgery. The authors suggest that the behavioral approach should be

the first line of treatment for women with VVS, and the surgery should be reserved for refractory cases given its invasive nature.

A recently published randomized treatment outcome study of VVS comparing vestibulectomy, group cognitive-behavior therapy, and pelvic floor biofeedback[54] indicated that, at post-treatment and 6-month follow-up, women in all three treatment groups reported significant pain reduction. However, vestibulectomy resulted in approximately twice the pain reduction of the two other treatments. In terms of sexual functioning, there were significant improvements in overall sexual functioning and self-reported frequency of intercourse from pre-treatment to the 6-month follow-up for all three groups; however, means for intercourse frequency remained below those of healthy women in the same age range. These findings indicate that restoring sexual functioning in women with VVS may require attention over and above that of pain reduction. While the vestibulectomy was the most effective at reducing pain, it was not significantly better at restoring sexual functioning. In a two-and-a-half year follow-up of this study[55], women in all three treatment groups continued to improve. Vestibulectomy remained superior to the other two groups with respect to pain ratings during the cotton-swab test, and women who had undergone group therapy reported similar improvements in dyspareunia as those who had undergone vestibulectomy. Changes in overall sexual functioning and intercourse frequency were maintained, with no group differences. These results suggest that while the benefits of group therapy may take longer to appear, it can be just as effective as surgery in reducing the pain of VVS.

Alternative Treatments

Alternative treatments for VVS include acupuncture and hypnotherapy. Although few studies currently exist, there is promising data regarding the effect of acupuncture on pain reduction and overall quality of life.[56] In addition, one study indicated that hypnosis reduced pain and helped re-establish sexual pleasure in a woman with VVS.[57]

GENERALIZED VULVODYNIA

Even though GVD is the second most common form of vulvodynia, there is relatively little clinical expertise in and research on this condition.

How is GVD diagnosed?

The diagnosis of GVD is one of exclusion and is based on the description, quality, and location of the pain. GVD is a non-cyclic, chronic vulvar pain extending to the urethral and rectal area, typically characterized by the patient's complaint of burning.[58] The pain of GVD occurs independently of stimulation, although light touch may exacerbate the pain. Some women with GVD also have VVS, but estimates of comorbidity have yet to be reported. For the diagnosis of GVD, it is important to rule out a dermatological condition called pruritus vulvae, which affects the same region as does GVD, but is characterized by an itching sensation and skin changes, such as excoriation and erythema (i.e., redness).[59] McKay[60] recommends the following evaluation for GVD: examination of the skin for dermatoses and a careful search for infectious agents likely to cause inflammation. This should be followed by a nerve assessment and by a careful anatomic distribution of involved areas, since locations and patterns of discomfort have been shown to be important in differential diagnosis.

What causes GVD?

The onset of GVD is usually acute, without a precipitating event. When such an event is recalled, it is often linked to episodes of local treatments, such as vulvar cream application or laser surgery.[61] Unfortunately, little is known about the cause of GVD. McKay[62] proposed that the pain results from altered skin perception, such as in neuropathic pain syndromes. This perspective has gained support because patients with GVD and those with neuropathic pain both report experiencing spontaneous, burning pain. In addition, GVD patients report symptom reduction when they are treated with medications typically prescribed for neuropathic pain[63], such as amitriptyline, a tri-cyclic antidepressant prescribed at low doses for pain control[64] (see below). Neuropathic pain originates with an injury to the nervous system itself, which leads to the transmission of pain signals even when acute injury is no longer present. Neuropathic pain in the vulva can result from many situations, such as damage to sensory nerves during surgery; damage to the pudendal nerve due to sports trauma, childbirth, or vaginal surgery; referred pain (i.e., when injury in one area causes pain in a different body area) from muscles or joints; and spinal cord injuries.[65]

In terms of other potential causes, as in the case of VVS, women with GVD have been found to exhibit abnormalities in pelvic floor functioning[66], which could potentially play a significant role in the initiation and maintenance of GVD; however, the direction of causation is not known. GVD has not been shown to be associated with clinical levels of depression[67] or with higher than normal instances of sexual or physical abuse[68], although vulvar pain in general may be related to episodes of childhood violence.[69]

How can GVD be treated?

Little information exists with respect to validated treatments for GVD. Oral medications for the treatment of neuropathic pain, such as amitriptyline and gabapentin, have been shown effective in reducing pain in women with GVD.[70] In addi-

tion, given the abnormalities in the pelvic floor musculature of women with GVD[71], pelvic floor muscle rehabilitation via the use of biofeedback led to reduced pain and improved sexual functioning in women with GVD.[72] However, no randomized controlled trials have been conducted to date with respect to any treatment for GVD. Despite the lack of knowledge concerning valid treatments for this condition, there is much agreement that it should be multidisciplinary[73], as in the case of VVS.

THE EXPERIENCE OF WOMEN WITH VULVODYNIA

Although common, many vulvodynia sufferers do not pursue treatment because of the embarrassment associated with talking about genital pain and its effects on sexual functioning. Of those who do seek treatment, many unfortunately do not receive adequate care: 40% of women with vulvar pain who sought medical attention did not receive a diagnosis even after multiple consultations.[74] These women may also be told, after several potentially invasive and painful evaluations, that all is well physically, implying that their pain is "not real" and that they suffer from psychological problems. Added to this frustrating situation may be a referral to a psychologist or psychiatrist who may focus on psychosocial functioning without fully addressing the complaint of vulvar pain.[75]

It is important to note that many chronic pain patients present without physical findings, as in the case of back pain[76], and that the diagnosis of vulvodynia can *only* be made in the absence of physical findings.[77] The lack of physical findings does not mean that the pain is imagined. While sexual, psychosocial, and psychological functioning are negatively affected in women with vulvodynia, they are likely the *result* of the pain as opposed to its cause, and treatment should address all areas of functioning, with a particular emphasis on pain management.[78]

In addition to problems encountered in the health care system, women with vulvodynia suffer from negative impacts on their psychosocial functioning and quality of life. Psychological distress, including depression and anxiety[79] are often reported. Pain-related changes in self-esteem and self-confidence, body image, and femininity have also been found.[80] Women with vulvodynia, especially those with VVS, also report that the pain significantly affects their sexual functioning and relationship adjustment.

Studies have found that women with vulvodynia report lower levels of sexual desire, and lower intercourse and orgasmic frequency, lower ratings regarding quality of sexual functioning, lower sexual self-concept and marital satisfaction, and more negative feelings about themselves and their sexual partners as compared with non-affected women.[81] Although many women with vulvodynia stated that intercourse exacerbated their vulvar pain, only a minority reported that the pain prevented intercourse.[82] In one study, vulvodynia sufferers who reported engaging in intercourse were found to do so for many reasons: 27.3% cited that they felt obligated to please their partner and 19.2% reported that the emotional and physical pleasure derived from such intimacy with their partner outweighed the pain.[83] Sexual activities outside of vaginal intercourse, such as masturbation and oral sex, do not elicit pain frequently in women with vulvodynia, and one study showed that women with vulvodynia engaged in these activities as often as did control women.[84] However, another study found that women with vulvodynia reported engaging in less non-penetrative forms of foreplay despite their acknowledgement that such activities did not elicit vulvar pain.[85] This suggests that affected women may avoid a large array of "safe" (i.e., non-painful) sexual activities.

Many studies have investigated sexual functioning in women with VVS, likely due to the fact that sexual intercourse is the most frequent and direct cause of the pain. VVS was found to alter sexual functioning to a large degree: 78% of women reported changes in sexual activity and satisfaction after pain onset, with most stating that they felt less able to participate in sexual activity.[86] Indeed, VVS was associated with the lowest overall level of sexual functioning and the lowest frequency of sexual intercourse compared to women with other types of dyspareunia and to control participants.[87] In particular, women with VVS reported lower levels of sexual desire, arousal, satisfaction, and pleasure, less vaginal lubrication, and lower frequencies of orgasm and masturbation. As well, they reported higher levels of erotophobia (i.e., feelings of guilt and fear related to sex) and negative feelings towards sex than control women.[88] Consistent with the high levels of erotophobia, other studies have found that women with VVS were less likely to make sexual advances, more likely to participate in sexual activity without wanting to, and more likely to report feeling guilty or inadequate as a result of not being able to perform sexually.[89] In a study comparing sexual functioning of women with VVS and GVD, no differences were found in frequency or type of sexual behaviors (i.e., sexual intercourse, orgasm frequency, fellatio, and cunnilingus) or the level of importance placed on vaginal intercourse. Pain-related changes in sexual functioning were rated as impaired when compared to the pre-pain levels of sexual functioning in women with VVS and GVD, and to current levels of sexual functioning in a control group.[90]

Women with VVS also reported negative effects on relationship adjustment. Although one study found no differences in relationship adjustment as compared with control women[91], another study reported overall ratings of "poor" regarding relationship quality in women with VVS

as compared with controls, who rated their relationship quality as "above average."[92] More than 40% of women with VVS reported severe, negative changes in their sexual relationship with their partners.[93] These findings may be related to feelings, on the part of the VVS sufferer, that their partners are less sexually satisfied[94], that they themselves are less sexually desirable to their partner, and that they feel less able sexually to satisfy their partner.[95] Despite reports of overall increased stress with their partners, women with VVS rate their partner as supportive.[96]

Given the physiological, cognitive, affective, and interpersonal complexity of vulvodynia, it is likely that no one "cure" will be found. A multi-modal treatment approach, tailored to each patient, and including careful assessment of the different aspects of the pain experience is recommended. Clinicians should also educate their patients as to the multidimensional nature of chronic pain so that the treatment of psychological or relationship factors is not experienced as invalidating.[97] Although pain reduction is an important goal, sexual functioning should also be worked on simultaneously through individual or couple therapy, as it has been shown that pain reduction does not necessarily restore sexual functioning.[98] Indeed, vulvar pain can have on negative effects on multiple aspects of life—but there is hope for women suffering with vulvodynia.

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