Journal of Lesbian Studies
Publication details, including instructions for authors and subscription information:
http://www.tandfonline.com/loi/wjls20

Medical Muddle

Nanette Gartrell [a]
[a] Williams Institute , UCLA School of Law and the University of Amsterdam
Published online: 08 Jan 2014.

To cite this article: Nanette Gartrell (2014) Medical Muddle, Journal of Lesbian Studies, 18:1, 57-65, DOI: 10.1080/10894160.2013.836436

To link to this article: http://dx.doi.org/10.1080/10894160.2013.836436

Journal of Lesbian Studies, 18:57–65, 2014

ISSN: 1089-4160 print / 1540-3548 online
DOI: 10.1080/10894160.2013.836436

Routledge
Taylor & Francis Group

Medical Muddle

NANETTE GARTRELL
Williams Institute, UCLA School of Law and the University of Amsterdam

Nanette Gartrell, MD, is a psychiatrist and researcher whose investigations have documented the mental health and psychological well-being of lesbian, gay, bisexual, and transgender (LGBT) people over the past four decades. Nanette is the principal investigator of an ongoing longitudinal study of lesbian families in which the children were conceived by donor insemination. Now in its 27th year, this project has been cited internationally in the debates over equality in marriage, foster care, and adoption. Previously on the faculty at Harvard Medical School and the University of California, San Francisco, Nanette is currently a Visiting Distinguished Scholar at the Williams Institute, UCLA School of Law. In 2013, Nanette received the Association of Women Psychiatrists Presidential Commendation Award for "selfless and enduring vision, leadership, wisdom, and mentorship in the fields of women's mental health, ethics, and gender research." At the age of 63, Nanette experienced a 3 $\frac{1}{2}$ month period of intractable, incapacitating dizziness for which there was never a clear diagnosis.

KEYWORDS Dr. Nanette Gartrell, lesbian psychiatrist, National Longitudinal Lesbian Family Study, lesbian leaders, lesbians fighting disease and disability, lesbians and medical treatment, lesbians coping with illness, lesbian support systems, best medical practices, metabolic, enzyme deficiency, dizziness, medication interactions

In the early 1970s, I entered medical school with a goal of providing comprehensive, nondiscriminatory healthcare to lesbians. I trained in psychiatry and became the first out lesbian physician on the Harvard Medical School faculty. Many closeted lesbians sought treatment with me because I accepted their sexual orientation without judgment. Outside of work, I informally

Address correspondence to Nanette Gartrell, 3750 Clay Street, San Francisco, CA 94118. E-mail: ngartrell@nllfs.org

offered suggestions to lesbian friends when they asked for medical advice. In that capacity, I pointed out differences between symptoms that require immediate attention and those that can wait until Monday. I also suggested questions that might be asked of healthcare providers, served as an ally at medical appointments, and provided reassurance when needed.

As these friends began to age, some developed serious diseases. During tearful calls prompted by dire diagnoses, I drew on my psychiatric skills and medical knowledge in offering comfort and support. I often wondered if I could continue to do these things if I were ill myself. Having good health gave me the energy to work long hours as a clinician caring for lesbian, gay, bisexual, and transgender (LGBT) people, and as a researcher studying lesbian families. My career has focused on examining homophobia both in individuals (clients who internalized judgmental attitudes toward LGBT people) and in our society and culture as a whole. I have completed numerous scientific investigations of same-sex parent families that have dispelled negative stereotypes.

Until my 63rd year, I was quite healthy. I felt fortunate—especially compared with friends who were battling breast, ovarian, and other cancers. The only symptoms that had ever worried me (briefly) were irregular heartbeats that turned out to be premature ventricular contractions (PVCs). PVCs disrupt the heart's normal rhythm so it feels as though it's doing somersaults. But after the PVCs were diagnosed by cardiogram, I stopped paying attention to them. They do not cause heart attacks and are quite common among older people.

To reduce the frequency of PVCs, I was advised to limit caffeine, alcohol, and stress. This was not difficult since my lifestyle was fairly healthy. I allowed myself a daily cup of coffee and an occasional glass of champagne. Stress reduction came through the same activities I had enjoyed for 33 years—running, tennis, and tap dancing. I operated at a high energy level that sustained my relationship, friendships, clinical work, and research.

My good fortune came to an abrupt halt on New Year's Day, 2012, when I was thrown to the deck of a boat in rough seas, severely injuring my back. Dee, my spouse of 38 years, had suffered from degenerative disc disease for 20 years, so I knew how incapacitating back pain could be. But I was determined not to let mine get the best of me.

I toughed it out for five months, hoping that the injury would heal without intervention. Gritting my teeth with every step, I ran and danced, knowing that I would pay at the end of the day. When the pain began to disrupt my sleep, I saw a physiatrist (physical medicine and rehabilitation doctor) whose examination revealed inflamed facet joints at the base of my spine. She prescribed anti-inflammatory and pain medications, and referred me to physical therapy (PT).

The physiatrist also pointed out that I might have been able to avoid such treatment if I had seen her immediately after the injury. At that time, she would have given me a course of steroids to reduce the pain and

inflammation. Lesson #1: Leaving any serious pain unattended is probably not a good idea.

Even more disconcerting was the physiatrist's recommendation that that I stop running, dancing, and tennis. Compressing and twisting an artificial spine to demonstrate the trauma of repetitive motion, she illustrated the destructive effects of my routine activities on aging facet joints. She recommended a gentler path for my future—*if* I cared to spend my senior years in as little pain as possible. It saddened me to relinquish my favorite exercise activities, but I had experienced enough pain to know that I could never just ignore it. Even though I had not slowed my pace at work, contending with chronic pain sapped my energy. I needed that energy to stay on top of my lesbian family study. Our findings had already made a profound impact on the struggle for equality in marriage, adoption, and foster care, and we had many more articles still in the pipeline.

I dove into physical therapy with a fantasy that compliance with the recommended routines might give me a chance to resume running. My daily PT regimen provided some pain relief, but not enough for any activity that involved running or twisting. After three months, I moved from PT to acupuncture.

My first treatment happened on a day when I was experiencing severe pain. As numerous needles were inserted into my back, legs, and feet, the pain began to evaporate. My jubilance was short-lived, however, when I was hit with a sensation of motion sickness. I began to retch. The acupuncturist removed some needles and asked me to sit up. The sensation did not abate, so he ended the session. Even though I had an anti-nausea acupressure treatment two days later, the queasiness lasted four days.

My physiatrist, who is a practitioner of traditional and alternative medicine, said that the acupuncturist had likely approached the pain too directly for a first-time treatment. She suggested steroid injections into eight facet joints that magnetic resonance imaging (MRI) had shown to be severely arthritic. The physiatrist said that I could be pain-free for many months if the injections were successful. In my case, the injections provided moderate relief, but not enough for uninterrupted sleep.

At about the same time, my heart began racing (tachycardia or rapid heartbeat). Even when I was completely relaxed, it clocked in at 150+ beats per minute, simulating a state of high anxiety.

My internist ordered another cardiogram that showed irregular heartbeats or arrhythmia. My resting heart rate ranged from very slow to very fast. The decision was made to treat me with me a cardiac medication that would steady the rhythm and lower my blood pressure, which had become seriously elevated during the work-up.

I have always been very sensitive to medications. I develop side effects even on the smallest doses. Because of this, when DNA testing first became available to the general public, I ordered diagnostic blood tests to determine

whether I was missing essential liver enzymes. I discovered that I am deficient in a cytochrome P450 enzyme that metabolizes nearly 25% of all medications on the market. Because of this deficiency, I can tolerate tiny doses of some meds, but others cause significant toxicity. There was no way to predict how I would respond to any particular medication, but individuals with my deficiency are advised to begin new medications at very low doses and increase slowly. Lesson #2: A DNA test is warranted if you develop problematic side effects on most medications; these tests are covered by health insurance, including Medicare.

For the arrhythmia, I was prescribed a sub-therapeutic (extremely low) dose of the cardiac medication diltiazem, which stabilized my heart rate and blood pressure. My elderly mother takes diltiazem, so it seemed safe, given our shared genetics. Diltiazem is a calcium-channel blocker. My doctor told me that it was unlikely to elevate calcium levels enough to cause muscle cramps—a problem I had experienced with calcium-containing drugs. Despite this optimism, within two weeks, I developed severe muscle cramps in my legs and abdomen, so the diltiazem was discontinued. Lesson #3: If you develop an unexpected, unmanageable side effect, discontinue that drug under medical supervision, and request a different medication.

In the twenty years I had been treated for hypertension, I had tried small doses of various drugs, each with a different mechanism of action. All but one of these caused intolerable side effects. Many of these drugs are also used to treat tachycardia. I had always been reluctant to consider beta blockers since they often cause depression. However, my mother and brother are both taking beta blockers for their arrhythmias, and neither is depressed. I agreed to try a tiny dose. I also gave up caffeine.

For three weeks, my heart rate and blood pressure remained erratic on a short-acting beta blocker, so I was given a long-acting pill with instructions to take one-quarter tab daily (a sub-therapeutic dose). Within 24 hours, my heart rate and blood pressure were stabilized. Six days later, I suddenly felt like crying for no reason. Over the following two days, my mood plummeted. I am ordinarily an upbeat person, so I suspected the beta blocker. Depression is one of the primary reasons people discontinue this type of medication. However, it's dangerous to stop suddenly, so I tapered off slowly.

I became anxious about other treatment options. I tried to calculate the time it would take for the beta blocker to be excreted and discovered to my dismay that, unlike many pharmaceuticals that are broken down by several enzymes, beta blockers are metabolized almost exclusively (80%) by the enzyme in which I am deficient. Ordinarily, the duration of side effects can be estimated from a drug's rate of metabolism. For me, there was no telling how long it would take to be eliminated. My strategy of starting low and going slow had clearly not worked. Lesson #4: Do not take a medication that is predominantly or exclusively metabolized by an enzyme you lack.

I became frustrated that the beta blocker would not relinquish its grip on my mood. I talked with my doctors about trying a tiny dose of an antidepressant for a short term—30 days—to boost my spirits. We selected an antidepressant that was least likely to cause problems with my enzyme deficiency, and within two weeks I felt lifted out of the doldrums.

But that did not last. By the third week, I was severely dizzy and nauseous. I could not work, read, or even watch TV. I forced myself to eat even though I gagged on every bite. I was so queasy that I could not sleep. Even though the anti-depressant I was taking rarely caused dizziness, my susceptibility to side effects led me to discontinue it. Then for four days, I felt great.

After that, I developed a sinus infection, and the dizziness came back with a vengeance. This time I had double vision as well. I tried to be patient, assuming that the sinus infection had spread to an inner ear infection (labyrinthitis), and since I did not have a fever, that it was likely caused by a virus. But as the days dragged into weeks, I became increasingly frightened. My internist ordered a comprehensive work-up including a brain MRI. Thankfully, there were no abnormalities on any of these tests. Most likely, she said, my symptoms would resolve over time.

My dizziness and blurred vision made it almost impossible to function. I concentrated on keeping my head and eyes as still as possible since movement triggered even more queasiness. Whenever I wore glasses, I felt as though I was looking through someone else's lenses—corrected for a severe astigmatism. Images were distorted. My eyes ached. I slept a few hours at a time between waves of dizziness. I had never had so much unstructured time during which I was capable of doing so little.

There is never a good time for illness, but I was particularly upset as the day for oral arguments on Proposition 8 before the U.S. Supreme Court approached. My lesbian family studies were cited in multiple briefs that had been submitted to the Court, and there was considerable media coverage. When reporters contacted me, I had to refer them to other researchers because I could not even read my talking points.

I took a medical leave from work. Sometimes I listened to books on tape, Ted Talks, or National Public Radio segments. I meditated. I kept in touch with people by phone. I listened to relaxation tapes sent by friends who also had trouble sleeping. I forced myself to walk 30 minutes a day to keep my back in shape. Dee and other friends accompanied me to prevent falls. Rarely could I muster the stamina to be driven to my favorite beach walk, because curves in the road exacerbated the motion sickness. On my dizziest days, when I could not find a comfortable position, I paced the hall of our home. Often I was too ill to talk to anyone but Dee. Hour by hour she offered cold compresses, massages, music, companionship, reassurance, and loving support. My heart ached for Dee as I watched the worry lines

deepen in her brow, and her skin become as ashen as it always did when she was in pain—although this time, it was because she could not take away my suffering.

Dee and I recorded symptom timelines. We developed a list of differential diagnoses that included:

1. labrynthitis secondary to the sinus infection;
2. anti-depressant withdrawal syndrome (even though the manufacturer claimed that this could not occur when taken in small doses for less than a month);
3. antihypertensive medication withdrawal syndrome (even though I tapered off slowly); and
4. a medication interaction syndrome (between the antidepressant and the anti-hypertensive) followed by a medication withdrawal syndrome.

Starting two medications at once had inadvertently muddied the picture, increasing the diagnostic possibilities. Lesson #5: *If* you can wait several weeks before adding a new drug to medication(s) you are already taking, it may be easier to determine which drug is causing side effects, should they develop.

We consulted with my internist, physiatrist, cardiologist, and psychopharmacologist, along with two neurologists and an ear-nose-throat (ENT) doctor. The general consensus was that I was suffering from medication withdrawal syndrome. One neurologist thought that I had vestibular migraines. He nonchalantly indicated that the dizziness could be a permanent condition. I was so unglued when I heard the word "permanent" that I accepted his prescription for an anti-seizure medication without questioning its usefulness. Within hours, my fear had turned to fury; the medication he had prescribed was completely inappropriate for my condition. Its *routine* side effects include somnolence and dizziness. Dee could find nothing in the literature about a "permanent" migraine condition. My internist disagreed with the neurologist's diagnosis and considered his opinion inappropriate. I shredded his prescription. Lesson #6: If a consulting physician's opinion seems out of line, focus on the consensus, not the outlier.

I was unsuccessful at following my own advice. A seed of fear had been planted that took root during sleepless nights. "What if I have to live like this?" I asked myself over and over. "How can I carry on as a wife, family member, friend, physician, researcher?" I hated being so ill that I could not take care of myself. I felt isolated in having a problem of uncertain origin—a condition for which there was no support group to which I could turn. I wished for an opportunity to hear from others who had experienced similar symptoms. Instead, I had to contend with my own negative brain chatter that became increasingly resistant to reassurance. Intellectually, I knew that recovery from the two most likely diagnoses—withdrawal

syndrome or inner ear inflammation—took time. In the worst case scenario, I was looking at 4–6 weeks. But in the middle of the night, that seemed an eternity.

My patients were offered referrals to other psychotherapists while I was on medical leave. I spoke to each patient, explaining that I was waylaid by dizziness and expected to make a full recovery. I told family members that I was coping as best I could. I was more candid with Dee and close friends. They knew that I was losing hope as the 6-week mark came and went without any lessening in symptoms.

I have contingency plans for my 27-year longitudinal lesbian family study should I die or become cognitively impaired, but I was unprepared for an illness that prevented me from corresponding with collaborators. Whenever I looked at a computer screen, I could only see pixels. That was how I was beginning to feel about my life—that it was fracturing into pixels. I brooded about opportunities that came and went while I was ill—including a chance to meet Justice Ruth Bader Ginsburg and an invitation to discuss my research on the Katie Couric Show.

During this period of despair, friends called daily and took me for walks. They helped to problem-solve everything from finding food I could tolerate to offering caregiver respite to Dee. My research collaborator called daily with study updates while I was unable to work. My brother took care of reassuring our elderly mother that I was slowly improving even though (atypically) I did not feel much like talking.

I hit rock bottom at eight weeks when I sprained my ankle on a walk. The one activity that provided a change of scenery from my eyelids or ceiling was now off limits. I told Dee that I could not tolerate another day of dizziness and sleeplessness. She contacted my doctor, who said that my only option was a strongly sedating medication to put me to sleep. However, it was likely to make me extremely groggy and possibly unstable on my feet. But treating the sleeplessness was now our first priority. I felt too bad to put up a fight.

For the first time in two months, I slept solidly for nine hours. I stumbled around during the day in a brain fog that felt hideous. But I was thrilled to have a break from endless hours of negative nighttime brain chatter. Even though the dizziness persisted, my mood began to improve after a few nights' sleep. I became more hopeful about my chances of recovery. I developed a new appreciation for the destructive psychological impact of sleeplessness. Lesson #7: Coping with illness is easier if you can sleep through the night, even if you are groggy throughout the day.

As the dizziness wore on, I became increasingly restrictive in my movements to avoid feeling worse. One day I had an unexpected revelation: I felt queasier when I changed glasses. I like colorful frames on my glasses, and I have several pairs that I wear regularly. I tested my vision with each pair and found that all but one made my double vision worse. I had updated

all lenses at the time of my annual ophthalmology visit 10 months prior. I gathered the glasses and took them to our optician (a block from our home) to check for refraction errors. To my horror, all but one set of lenses was corrected for a severe astigmatism that I didn't have. To top it off, my most recent prescription was not even on file. How did I fail to notice this prescription error? Before I became ill, mostly I wore contacts, so I had not noticed the distorting effect of the incorrect lenses. When I became dizzy, I only wore glasses, inadvertently compounding my symptoms. Lesson #8 (I am still astounded to find this necessary): When you pick up a new pair of glasses, take a copy of your prescription. Ask the optician to check the lenses under the scope and write the refraction numbers on a piece of paper. Compare your prescription with the optician's numbers. You may also find it useful to bring all prescription glasses (including reading glasses, sun glasses, computer glasses, prescription eye guards, and prescription safety glasses) to your annual ophthalmology exam so that the eye doctor can check to make sure they are accurate.

I was elated to have figured out one piece of my medical puzzle. After the wrong lenses were replaced, I began to see more clearly. I fantasized that this bizarre discovery would eradicate my symptoms, but that was not the case. I was stuck with the dizziness for another full month. Then slowly, day by day, my symptoms began to diminish.

I had to relearn how to read, watch TV, bend over, turn quickly, and ride in a car without feeling dizzy or queasy. The dizziness is still recent enough that I feel frightened if I catch a virus, feel unusually tired, or feel queasy. I am sure this is because the mystery of my illness remains unsolved. We (my internist, psychopharmacologist, physiatrist, ENT doctor, Dee, and I) *assume* that the dizziness was the result of a cascade that began with tachycardia, followed by medication toxicity due to my enzyme deficiency, leading to medication interaction side effects, and ultimately a medication withdrawal syndrome. Yet the possibility of an inner ear inflammation remains a confounding variable. And of course the dizziness was only made worse by wearing the wrong lenses.

The biggest takeaway from this whole experience is that I must be extremely cautious in considering any new medication. I must research any proposed drug far more thoroughly than ever before, weighing the risks and benefits carefully. My fear is that someday I will develop a disease for which the only possible treatment is a medication I cannot metabolize. My wish is that genetically tailored medications become a reality for all patients in the near future.

I also learned that I had the resilience to survive three and a half months of intractable dizziness despite intermittent feelings of hopelessness. Even though there was no way to predict if or when the dizziness would resolve, my only option was to ride it through. I was impatient to have my life back, but lamenting my losses only made me feel worse. Because I was too sick to

engage in any meaningful activity, distraction was the best medicine, along with Dee's constant assurance that I *would get better*.

I hope this experience will be a useful lesson to me during future illness. I never imagined that I would be incapacitated by a condition that was amorphous and untreatable. As a physician, I expect rapid diagnosis and efficient treatment. I have always assumed that I would have the stamina to work even if I were ill. I now understand that I cannot count on any of this.

I have developed a new appreciation of recovery time. I am still rebuilding my ability to ignore minor ailments. I remind myself that I will face other health challenges. And I celebrate each day that I wake up feeling clear-headed and pain-free, because I am all too familiar with the alternatives.

I do not know how I could have managed without the tender care and medical expertise of my physician wife Dee, the loving concern of family and friends, the professional expertise of several outstanding doctors, and my own dogged persistence in trying to decipher why I was so intractably dizzy. I shudder when I think of the alternatives—not having a health ally, research and diagnostic expertise, health insurance, medical language skills, or excellent physicians. Countless patients suffer from medication toxicities and withdrawal symptoms that are incorrectly diagnosed. I hope that this article will serve as a helpful guide to others who have trouble tolerating medications. If you do, seek genetic testing for metabolic enzyme deficiencies. The information you obtain may very well save your life.

ACKNOWLEDGEMENTS

I thank Joan E. Biren for her assistance in the preparation of this article.