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It was 1997 when I started learning about disorders of sex development (DSD), then known more widely as intersex conditions. It was that year when I first met Bo Laurent, founder of the Intersex Society of North America to talk about my idea of interviewing physicians, parents, and adults about medical care. I did not know it then, but I was about to begin what has been a 15-year involvement in this area. It was a different time then. Individuals with DSD had only recently started speaking out about their experiences with their medical care. They spoke courageously about medical visits in which their genitals were repeatedly probed and inspected in ways that felt violating, about insensitive and even dehumanizing comments about how they weren't normal or weren't "really women" or "really men," about lies doctors told their parents, about surgeries that had left them harmed and deeply alienated from their bodies, about how they had wrestled with shame, stigma, even self-hatred into adulthood, and about how they were thrust into recovering from well-intentioned care, care that wasn't their choosing. In short, they spoke about how they had suffered—some irrevocably—at the hands of well meaning parents and doctors who believed they were providing the best care possible.

Sometimes how we know what works and what doesn't in medicine comes not from physicians' own assessments of what's good care, but what patients share through their own voice, the voice identifying them as unique human beings. If our ears and hearts are open we can hear those words -- which are sometimes extraordinarily difficult to take in -- and ask ourselves, "Have I done anything that could cause such pain? Can I stay with this person and listen because at this time their hurt, their experience, is more important than my pride or my ego, or my next patient."

When the brave and courageous adults started speaking out for the first time it was remarkable. And many doctors' ears had trouble staying open. We'd had several movements around health by then -- the women's health movement, AIDS activism -- but this didn't mean that activism was how doctors felt medicine should change. Quite a few physicians dismissed the criticisms and even the personal experiences uttered from such a place of pain. They said it was the disgruntled few and the so-called bad outcomes.

Some physicians, however, rather than shielding themselves from the suffering of others, were brave and open enough not simply to listen, but to enter into the conversation. They had what I have come to think of as courageous conversations. These are conversations that embraced that suffering and asked, “What can I learn here? What can I do to help?” What they showed was a concern beyond themselves or their egos. They showed compassion.

Compassion is the capacity for feeling what it is like to live inside somebody else's skin. It involves the emotions of empathy and sympathy for other's suffering, plight, or simply where they find themselves. Compassionate acts attempt to alleviate that suffering as if it were one's own. And compassion is a cornerstone of greater social interconnectedness and humanism. It is a part of love itself.

Now one might say, “What does love have to do with medicine?” And what I would say is everything. Love is the cornerstone of healing. When I speak of love, I don't mean it as an emotion or sentimental feeling tied to romance. I am using it the way the cultural critic bell hooks (PhD) has used it, as a love ethic that refers to a set of practices that derive from the extension of oneself for the well-being of another.

The Golden Rule is an ethical code that essentially states: One should treat others as one would like others to treat oneself. This basic teaching is at the heart of all the world's great religions and philosophies, and has been handed down from generation to generation for thousands of years. In medicine it could be translated to: treat all patients as you would have the members of your own family treated. In this sense, the various forms of the Golden Rule are clearly based on the concept of compassion and love.

This is different than “first do no harm,” espoused in the Hippocratic Oath that all doctors take when they embark upon their career as physicians. While not harming the patient is explicit in this dictum, it provides very little guidance about what to do to ensure healing, and even well-being. Surely the absence of harm is important for healing, but the absence of harm alone cannot heal. Healing requires something different, something with which medicine has fallen out of practice of late.

In the 1950s the idea that the patient is a person versus a disease emerged. One text, for example, noted that “The art of medicine is not confined to organic disease; it also deals with the mind of the patient and with his behavior as a thinking, feeling human being” (*Principles of Internal Medicine*). One prominent doctor of the period suggested physicians own thoughts and feelings could themselves be diagnostic tools not to locate pathology, but rather to identify the scope of the human problem, including illness.

But somewhere over the last few decades in part due to technological advances

and changes in our (American) health care system, medicine turned away from the human and towards looking deeper and deeper into the body and its parts and processes to understand human ailments and suffering. This has led to new drugs and treatments that have saved lives. But it has usurped and defined what we think of as medical care and healing, and many American ideas are beginning to be followed in many countries around the world. One result is we have come up against what has been called a technological imperative—the penchant to order ever more diagnostic tests, to perform procedures, to intervene. This imperative is one of the most important variables in contemporary medical practice and is a source of numerous moral quandaries because it only answers what we can do, not the more important question: What should be done? The technological imperative determines thought and action and a language through which choices are framed—not doing surgery, for example, is almost always framed as doing nothing. As such, it forces physicians to conflate maximum intervention with good, appropriate care; the technological imperative narrows doctors' field of possibilities and thus removes options.

Since the 1980s economic restrictions have changed the way we interact with our doctors.

Cost-cutting has meant reducing time spent with patients, reducing nurses, reducing or eliminating social workers, not providing psychosocial care -- all those things we think of as central to good care. In short, we are in a time where there is fragmentation of care and more importantly, fragmentation of the patient as person.

These changes in the American medical culture here and then have filtered down to students who come from around the world to study at the universities, distorting their outlook as they progress through medical school. Indeed, numerous studies from the last decade or so document an increase in cynicism and loss of idealism in medical students during their education. A significant decline in empathy occurs during the third year of medical school. The erosion of empathy occurs precisely when the curriculum is shifting toward patient-care activities when empathy is most essential.

So somewhere down this parallel road of cost containment and toward looking to genes, molecules, and body parts to understand human diseases, we lost sight of the human as a person, one situated in a family, a community, and a society. And we moved from a place of healing to one of curing. If we can cure this illness the person will be healed goes the belief. This has been a disservice to the suffering of others, to doing right by others. Doctors all too often feel that medical skills and scientific knowledge are the only things that result in so-called good outcomes. I think all patients have always wanted is emotional support and caring, but it hasn't always been in the doctors' lexicon. We have yet to dig into the human dimensions of medicine.

What is to be done?

Well, this brings us me back to love, to empathy, and to compassion in medicine. This is not the job for one individual but the joint efforts of many people to effect this change’.

This is not your job alone to make this happen -- that would be something impossible for any one individual to accomplish since in some ways it seems to be stripped away in training -- but I do believe we can join our efforts with many others trying to effect this change.

Empathy is much more than a soft and fluffy word, and it means much more than offering “kindly words” to patients. Empathy and empathizing help physicians to improve the life experiences of their patients. Empathy demands communication. It demands listening and talking to patients and parents. It means understanding the thoughts and emotions of patients, which demands conscious cognitive effort. Physicians benefit from knowing their patients—understanding their attitudes, backgrounds, and circumstances. Physicians must also know a patient's experience of illness, and this is acquired, quite simply, by talking to them.

By endeavoring to understand the thoughts and emotions of patients, physicians can serve them better. They can provide patients with appropriate information and advice. They can make recommendations that are suited to the individual. Physicians can adopt an approach with which patients feel comfortable.

Let’s try to see this from another view- not from the perspective of someone with an intersex condition, but from the perspective of anyone being treated for a condition that affects the way they identify themselves.

I want to tell you a story....

In 2006 I was diagnosed with breast cancer. I was 36. I had had some discharge from my nipple that I had noticed and also had not noticed. You know how that happens right? Well one day blood came out and then it clicked, “This isn’t right.” That started a journey that led me through 9 months of treatment including 4 surgeries, 4 months of chemo, 31 days of radiation and has left me with a body marked by my care, that doesn’t feel like me, that I struggle to find beautiful, to love, and even to share with others.

I recently re-read some updates I sent out to everyone when I had cancer and came across this one:

As per usual, the surgical oncologist was late. This time it was 2 hours late. As I waited I felt increasingly vulnerable and when I got into the room, I told the surgeon as much. I asked him how he was and he said, “Everyone wants to be a breast surgeon today,” which was a bad sign. He was curt and dismissive about my first question. When he laughed at my next question, I popped my half naked self up off the table and said, “I

can't do this anymore. I can't figure out where the healing is in all of this. I am sick of being molecularized. I am not getting what I need from you."

My dignity had been taken.

I share this because according to my 9 months of treatment I had been cured of cancer so to speak, but my fears, my pain, the secondary result of what it means to have had cancer still holds grip in my life. This whole part of my illness has been carved off as separate from the real task of treating me. The physicians have apparently cured my cancer, but no one had healed me. Is my being alive the best we could hope for?

Several years after my cancer diagnosis, I divorced. After divorcing I thought I was fine until I realized that I didn't feel capable of sharing my body with someone. I panicked and froze. Quite a few friends who had divorced had gone through these periods of sexual abandon afterwards. For me it was and is much more weighted. I cannot share my body with someone and not face cancer because certain things need explaining, violating my privacy when I don't feel like bringing cancer into the frame.

I'm not going to lie. Some days, it feels insurmountable because my thought is, "Who will accept and love this body? Won't they eventually reject me because of it? Who am I to think my body is lovable."

Because I want more for myself I have argued with this part of myself and fought through this. And as I thought about my journey I realized how many parallels there were with the people with DSD I had known and loved over the last 16 years.

I recently went to a workshop. As part of it, we had to pick a commitment. This wasn't some light thing, but rather a dedication. We had to start with the phrase, "I am a commitment to..." It was purposefully not, "I am committed to," but "I am a commitment to." Do you catch the way the commitment is embodied?

I tried out things like being love, giving love, fulfilling my joy, speaking my truth. Noble things surely and from my heart, but the instructors said usually when you've hit on the right commitment, you feel something saying it. So I went home one night and I started writing. I told myself to be honest and within 5 minutes I had written what I am about to tell you and I started bawling. I had been preaching a philosophy for 16 years I had not been living myself. Here is what I said...

I am a commitment to fully experiencing my body and loving it fiercely.

Even to this day, this is still hard for me to say.

And here's what I realized during that training as I felt selfish for having a commitment like this when others' commitments were outwardly focused on human rights, social justice, and making a better world. That how I feel about myself is directly connected to what I am capable of giving and doing and achieving in the world. That in order to fight my best fight for everyone in here, I need to also fight for myself. Loving myself enables me to achieve so much more. It affects how confident I feel, whether I walk with head and my eyes up, whether I feel capable of speaking up, whether I feel I have something worthwhile to say, whether I can have a courageous conversation with doctors, whether I can feel love that enables me to turn around and give even more. When we cut ourselves off not to feel pain we also cut ourselves off from other feelings, ones we would very much enjoy and deserve.

I tell you all of this because I think my journey has something to say about your journey and the journey of those that love you. And I want to tell you that the foundation of that journey is that there are no wrong bodies and in a highly circulated blog post from Hanne Blank, there is no wrong way to have a body. Anyone who tells us that our bodies are not okay are not views we need to accept.

There are some things that I want to suggest you do, but I now know your ability to do them rests of you loving yourself and turning that compassion inward first.

And this brings me to one of the reasons I love this group. I think you are a central piece in helping people to reach this commitment. I love that I can say to physicians I have a group you can send any parent to and they'll be taken care of. That is how we are going to get future generations to this commitment sooner. That this focus can lead to self healing and learning.

I want to suggest as you go down this journey for yourself and self-discovery you take that energy you will unleash and do a few things to bring compassion to the care of DSD because right now we can't rely on physicians to do that. We need you.

Get on a team or act as a local resource for families. This is free and you are the conscience of that team. One of the most daunting tasks in the practice of medicine is having courageous conversations with patients and their loved ones, a skill that is not formally taught in medical school. Your job is to tell them what works and doesn't. What feels good and doesn't. They cannot argue with your experience. Every room I have been in where a patient or parent has talked has been rapt. No one ever dismisses the experience anymore. It may be hard to think of talking to the white coats, but I've found they listen. That somehow your words can reach that place deep inside that got squashed or quieted in their training.

You can tell them that sometimes showing compassion can mean listening or holding a hand. That words may be necessary, but sometimes they are not nearly as powerful as the unspoken impact of an embrace or the touch of a hand. That at some point families will need their compassion more than their explanation. These may appear to be small gestures but I believe people remember these compassionate acts long after they have occurred. They are the taste left afterwards. If you have been helped by this group, by a doctor, by another parent I want to suggest you see it as your duty to help another.

I also want to suggest you inaugurate a Compassionate Caregiver Award that is given to someone who practices these qualities. It could be national or regional or by specialty. You define the terms of quality care and then choose individuals who subscribe to that. This will go far to showing how you want this world of care to look like.

But before all of that I want you to realize that before you can save others you need to save yourself. So I want to read you a poem by Mary Oliver.

The Journey

One day you finally knew
what you had to do, and began,
though the voices around you
kept shouting
their bad advice--
though the whole house
began to tremble
and you felt the old tug
at your ankles.
"Mend my life!"
each voice cried.
But you didn't stop.
You knew what you had to do,
though the wind pried
with its stiff fingers
at the very foundations,
though their melancholy
was terrible.
It was already late
enough, and a wild night,
and the road full of fallen
branches and stones.
But little by little,
as you left their voices behind,
the stars began to burn

through the sheets of clouds,
and there was a new voice
which you slowly
recognized as your own,
that kept you company
as you strode deeper and deeper
into the world,
determined to do
the only thing you could do--
determined to save
the only life you could save.

I love this poem and far be it for me to think I can re-write something so eloquent, but I want to suggest that you must save your own life, and that once that work is ongoing, you can save others. I see it all of the time.

Let's heal ourselves and then help doctors figure out how to heal again too.