Of Weakness and Vulnerability

This is a lecture I gave to medical students at Michigan State. It was a yearly lecture series on the relationship between spirituality and medicine.

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I'm going to speak with you this afternoon about spirituality and medicine. So I should probably start with my simplistic definition of spirituality: It's anything that brings you closer to your true self, to the deepest parts of you, to your values. Specifically, I want speak about the spirituality of vulnerability and weakness. We don't like to think about our frailty and our failings, of course. We live in an officially optimistic culture in which we're supposed to see the bright side of things, find the silver lining, and have faith that everything will work out in the end. Hopelessness is unpardonable; giving up, the ultimate sin. But that spirituality of optimism is false, for it denies and excludes a fundamental part of us: our brokenness.

Stories are the best way to teach, I think, so I'm going to offer you stories of vulnerability, pain and, I hope, transcendence. I hope that one or two of them speak to you in some way.

Minnesota

I was a family physician. My first practice—over 35 years ago—was in a tiny Minnesota town on the north shore of Lake Superior on the edge of the Boundary Waters Canoe Area wilderness. We three physicians cared for about 4,000 permanent residents in a county the size of Rhode Island. In the summer the same three of us were besieged by upwards of 20,000 people at any given moment, all of them on vacation and ready to have their heart attack, or break a bone, or sit in poison ivy. We were 110 miles along a twisty lake-side road from the nearest specialists. Practicing without easy specialist backup was exhilarating but, for me—eventually—terrifying, like walking a high-wire without a net.

The patient I want to tell you about—I'll call her Satu—was a neighbor. She came into the office six or eight weeks after her last menstrual period with all the symptoms of pregnancy, but

her pregnancy test was negative. I wasn't particularly worried since the primitive pregnancy test we used then could sometimes be falsely negative up to eight weeks. A couple of weeks later, though, it was still negative.

When it was again negative at about 11 weeks, I believed she had had a missed abortion and had not passed the dead products of conception. A D&C was necessary, so a week or two later she was in the OR. When I examined her under anesthesia, her uterus felt bigger than it should have, but I was so intent upon and nervous about the procedure that the enlarged uterus didn't register or ring any warning bells. I began the D&C and soon found myself extracting parts of a fetus that had been alive and well a few minutes before. I had killed a living, longed-for baby. Afterwards, I could hardly talk to Satu and her husband. I gave them an incomplete story because I still didn't understand how this had happened.

I have a long list of my mistakes, most of them inexcusable. I hadn't trusted my patient's ongoing feelings that she was pregnant. I had relied completely on only one kind of test. Ultrasound wasn't yet in widespread use and we didn't have one in town, but there was one 110 miles away in Duluth and, given the special circumstances, I should have referred her for one or just sent her to an obstetrician in Duluth. Essentially, I hadn't even considered the possibility that the fetus was alive and hadn't taken any of the precautions I should have.

I was overwhelmed by grief, guilt and shame. This was an unnecessary tragedy; if anything was negligence, this was. A week later, I talked with Satu and her husband at length. At that time, people in small towns didn't sue their doctors, but I almost wished they would have. I asked myself seriously: Should I even continue to practice medicine?

I needed to talk about what had happened with somebody, but it seemed no one could bear to listen to me. The Duluth obstetrician tried to reassure me I had done all the right things when clearly I hadn't. My partners were embarrassed and cut any meaningful conversations short. My wife Marja was not a medical person and couldn't really understand the nuances of my mistakes.

I felt guilty and ashamed for a long time. Even talking about it now—35 years later—raises some of those same emotions. For months I was on edge 24/7. I, who had always done things right and was always in control, had committed the unforgivable. I had to accept not only my ultimate powerlessness, but also the potential of doing something like it again in any future decision. My intelligence, education, confidence, and reputation made me no less vulnerable to

tragedy and shame than anyone else.

There was no silver lining.

I didn't do a very good job of facing this darkness within me. It took me many years to realize that this vulnerability and weakness were also elements of my true self. I alternated between denial (trying to convince myself that it could have happened to anyone) and utter shame. Someone once said that guilt means I *did* something wrong; shame means *I* amwrong. Guilt has an important place in our spirituality because it recognizes what we've done and spurs restitution. Shame obscures our true selves and serves no useful purpose. It deceives us into believing that the darkness is all there is to us. I spent a lot of time in that place of pain.

Unable to integrate myself, I couldn't be much help to Satu and her husband, either. To be in their presence was just too painful.

Several years later, I left that Minnesota practice feeling burned out, not only by that mistake but also by the other pressures of rural medical practice. Our family took a year's sabbatical to Marja's hometown in Finland so I could recover. As a way of processing it, I began writing about what had driven me from medicine. Satu's story was, of course, part of it. I knew I couldn't be the only doctor who'd made such an awful mistake, but there was literally nothing, (nothing!), in the medical literature except a few case reports, written by doctors sitting in judgment, that castigated the sinner mercilessly. Separated by years and an ocean from Satu's face, I thought it was about time somebody brought medical mistakes out of the closet. I sent what I'd written to the *New England Journal of Medicine*. The editor eventually called me back: "Dr Hilfiker, we like your article but I want to be certain you understand: This wasn't just a poor result; it was a *real* mistake." I told him I knew that. "Making it public may jeopardize your career." I told him I understood that, and the article was published. The response was overwhelming. Two obstetricians wrote in to say my license should be revoked, but over 150 other physicians wrote in at that time to say that I'd given them permission to face their own shame and guilt. Many more have written over the years. That piece is, actually, what I'm most known for in the medical world; almost thirty years later it's still used in a few medical schools.

Washington

After Finland Marja and I returned to join a small faith community that worked with economically impoverished people in the inner city of Washington. We were searching for a closer relationship with God. Liberation theology claimed we could find God by moving into solidarity with the poor … or at least that was my simplistic inference.

I became a clinic doctor: no night or weekend call, no hospital work and plenty of specialists. The medical aspect of the work was certainly easier than rural practice. But it didn't seem to be bringing me any closer to God. Indeed, the behavior of some of my patients was driving me toward that typical American point of view that judges the poor as the cause of their own poverty. Patients skipped half their appointments, wouldn't bring their kids in for well-child checks, lied to me about their medications, and came in drunk or high. They didn't put their health high on their priority list. That wasn't the majority of my patients, of course, but it was a sizable chunk. Fortunately, I stuck with it and my patients taught me a great deal. One story is representative.

Margine was a young woman who had been a patient of mine for several years. She visited my office with Robert, her son, almost two.

Robert had a minor viral illness and was understandably a little crabby. As I interviewed Margine, Robert slipped off her lap and wandered over to the toys in the corner of the room. Soon, many of the toys lay scattered about as Robert rummaged unsuccessfully for something he might like. Suddenly Margine noticed, sprang up, and grabbed his arm, yanking him away from the toys, scolding, "Stop messin' with the doctor's toys. You always be gettin' into trouble." I tried to suggest that the toys were there to be messed with, but Margine locked her son onto her lap.

Some minutes later as I was examining him, I tried to get a look into his ears. Predictably enough, Robert jerked his head back and started crying. Margine's response was to shake him again, whack him on the bottom and scold, "You sit still for the doctor! You always be bad like this!"

I found myself furious with Margine's abuse of Robert. This wasn't the only incident! But a little reflection soon convinced me that—while my anger might have been appropriate—directing it at Margine wasn't.

For Margine was at the time still fourteen. I'd been her doctor since she was eleven, and I knew about her own history as an abused child. Margine's mother had been a heroin addict since before Margine was born, so Margine was passed around from relative to relative, many also addicted. She lived in constant chaos. Margine had become sexually active by the time she was eleven, and all our attempts to provide her with counseling or birth control were futile. Having a baby would give her meaning and identity in the community.

Margine and Robert were locked in. They lived in a neighborhood of unspeakable violence where everyone had a family member or close friend who'd been killed. Many inner-city boys simply didn't expect to live into adulthood. In our cities we segregate the poor so they live in neighborhoods where everybody else is poor, too. There are few jobs, none of which pay enough to live on. The school system was … is chaos: over half don't graduate and, of those who do, some don't know their multiplication tables or are functionally illiterate.

We could go down the list of things that most of us believe everyone deserves—a decent education, a neighborhood relatively free of violence, a job on which one could support a family, housing that one could afford: none of these were available to Margine.

So whose "fault" was this abuse of Robert? Margine … a fourteen-year-old abused child? Stories like Margine's were a turning point for me. Would I have turned out any differently if I'd been born in her place? I no longer blamed her for her poverty.

Margine's deep vulnerability and brokenness were … built in. Her situation was, to be honest, hopeless. I couldn't even treat Robert's cold without dealing with her abuse, which would have required her emotional wellbeing, which depended on dealing with most of the other fifteen serious problems she faced. The proper multi-discipline intervention might have helped her with a few of those problems, but she wasn't going to get the proper intervention. There were too many Margines and too few resources. Her downward course, and Robert's, were virtually predetermined.

But I was trapped, too. How was I going to help her care for Robert's illness in the face of her brokenness? I was incapable of giving the care she really needed. Ultimately, however, that helplessness I experienced gave me some little sense of what she was going through. She had no real choices; I could no longer judge her behavior. Her abuse of Robert was inexcusable, of course, but I understood why it made sense in Margine's world.

What good did it do Margine that I had come to understand and experience some of the same darkness she knew? In that encounter, probably not much. But over time, as I learned what Margine had to teach, I recognized that our mutual vulnerability offered me a deep connection with her and her brothers and sisters. People come to the physician because they're vulnerable; our technical skills offer important treatment, but much of the healing we can offer—even in a desperate situation—comes through the quality of our presence, and that's deepened by an awareness of our weakness. I am quite convinced that my care of patients was better because they knew, at least at an unconscious level, that I had experienced the brokenness in myself.

I didn't recognize it at the time, but the experience with Margine and others like her set the stage for the next fifteen years of my life. I now knew that the poor were not to be blamed for their poverty; most who grew up in the environment of the black ghetto had desperate futures. So I turned much of my writing and speaking attention to finding out the historical forces that had created the ghetto and telling those stories. At the same time, I sought ways to move into closer relationships with my patients. Opening to her weakness and mine gave me an important kind of strength.

Joseph's House

In 1990, Marja and I found a large, single-family house that we called Joseph's House we moved in and began welcoming homeless men with AIDS to live with us and our kids. We admitted the men when they were just beginning to need care. There were no effective medications then, so the vast majority lived about a year with us. Most could die at home. We were part shelter, part home, part community. Joseph's House is still a vital institution, but Our 3 years there was the most intense time of our lives.

Included in the reasons I wanted to live with the men was the chance to develop *peer* relationships with people so different from myself.

- I was white and they were black;
- I was educated and they had little formal education;
- I'd grown up in a safe, secure two-parent environment; most of them hadn't;
- I was financially secure and they were living on the streets; and so on.

Despite my experience with Margine and others, I still felt a definite sense of superiority. I would never get myself in such desperate straits. Now … I was psychologically and theologically sophisticated enough not to *believe* that I was superior, but I certainly felt I was. I wasn't proud of those feeling but there they were.

PeeWee

PeeWee was forty-three when he came to Joseph's House. He'd been homeless for about a year. He was ultimately hospitalized and, despite his poorly treated pneumonia and newly-diagnosed AIDS, was then discharged to the large shelter downtown where we found him and brought him to Joseph's House.

He spent much of his first weeks with us in bed, the covers rolled up over his head. PeeWee, as far as I knew, had never used drugs himself, but he'd been a dealer and a hustler all his life, living by his wits within the violence of the Washington streets. He'd been a drug kingpin, in fact. He said he'd been responsible for the deaths of several people. I believed him. Much of that inner violence remained. His stock answer to any of the other men who angered him was "I'll kick the shit out of anyone who messes with me." He seemed to have no other tools for dealing with conflict. But PeeWee was also a natural leader, brutally honest and intensely loyal; he was able to recognize when he'd been wrong and knew—better than any person I've ever met—how to apologize for his errors. He and I had several run-ins and he almost left the house once … but that was because he felt I'd been disloyal to our friendship. We developed a pretty good—if at times testy—relationship.

By the time we founded Joseph's House, I was discovering that the emotional turmoil—including several years of deep unhappiness I'd experienced in college and probably even my burnout in my Minnesota—was due, in part, to a significant organic depression. Over the years, I'd done everything I'd known to do—prolonged intensive psychotherapy, medications of various stripes, prayer, spiritual direction, aerobic exercise, sabbaticals, meditation ... you name it. It seemed that the depression would never be completely healed, that it'd always be there, sometimes crouched just beneath the surface, more often chronically interfering with everything at a low-grade level, occasionally leaping out to overwhelm me. I would decide a couple of years later to leave the practice of medicine. The combination of my depression and the stress of doctoring were just too much for me.

Some months after PeeWee joined us the depression started breaking through again ... and became particularly agonizing. I intensified my psychotherapy and adjusted medications. I cut back on my work schedule; I kept running for an hour every day. Nothing worked. The intensity mounted, and I became for the first time in my life dysfunctional. I *couldn't* go to work. ***That*** sc ared me. I stopped work at the clinic, but I was still living at Joseph's House. The pressure of trying to be present to the men in the face of my depression, however, was too much.

I had from time to time shared in our twice-weekly community meetings about my depression but always with a certain clinical detachment that left me pretty much in control. This time there was no illusion of control. I talked about the severity of my depression and about my fear of the chaos: I was looking into an abyss, and I could see neither the bottom nor the other side. I told the men I wouldn't be able to respond to them either as a doctor or as a person of responsibility in the house for a while. And I asked them just to allow me to live in the house as another resident without coming to me for things.

I stopped talking, not knowing what to expect. Right away, PeeWee spoke up, "That's cool, Doc. We been noticin' somethin' wrong. You just take as much time as you need. We'll still be here for you."

That was it—just those few words. Over the next few minutes, each of the men responded similarly. There was no over-reaction, no soulful looks of deep understanding or pity, no embarrassment for me, no offers of help, just simple acknowledgment that I was going through a rough time and that they'd be there for me. Howard said he'd pray for me.

To other, it may seem a commonplace event; not for me. The healing of my spirit was profound. I'd acknowledged my utter brokenness, and the men weren't frightened by it, embarrassed by it, disgusted with it, or even eager to cure it. Just, "That's cool, Doc. We'll be here for you." What they offered me was unpitying acknowledgment of our mutual vulnerability … and the awareness that some things will never be healed. "You got depression; we got AIDS. Let's get on with it."

The love and acceptance the men offered began an extraordinary process of healing in my soul. I began to understand my depression more deeply as a broken—probably *permanently* br oken—part of me. I was like each of the men in that room, vulnerable and unable to heal myself. Experiencing our mutual powerlessness was a profound experience. I had stumbled into a new world of inclusion. I no longer felt that sense of superiority to those born into poverty

or pain.

We all know human vulnerability. Faced and accepted, it makes new relationships possible. I had been trying unsuccessfully to move into peer relationships with people like the Joseph's House residents for ten years. Ultimately, it was my deep woundedness—my depression—that cracked the barrier.

Healing requires meaningful relationship and meaningful relationship requires that we acknowledge our own darker side and recognize that same dark side in our patients. Encounter with our own vulnerability makes us better doctors.

Alzheimer's

The last story is also about vulnerability and powerlessness, but embracing it has been anything but painful.

It began in September 2012 when a neurologist told me that the cognitive impairment I had been experiencing was most likely due to Alzheimer's disease.

- I'd gotten myself lost in familiar places,
- I was misplacing things repeatedly,
- I couldn't even *understand* somewhat complex Excel formulas that I'd written *myself* tw o years before,

- I couldn't keep more than two or three things in mind at once.
- In a bizarre episode, I visited a friend who'd been transferred to a new prison way out in southern Virginia: 3 hours down, 3 hours with him, 3 hours back. This was my first time there … Except that it wasn't. Both my friend and his chaplain told me I'd been there. Three months earlier. I'd completely blanked it.

To jump right away to the end of the story, I found out this past autumn—after a year of living with Alzheimer's—that I don't, in fact, have Alzheimer's. The cognitive impairment I experience—while very real—has worsened only slightly in the past year. The cause is

unknown, but the probability is that, at some point, my cognitive decline will continue. For a year, however, my doctors and I believed I had Alzheimer's. So I'm going to tell this story from my point of view as an Alzheimer's patient.

Alzheimer's is not a pretty picture:

- a slow decline of intellectual function, language and behavior,
- an inability to care for oneself,
- the imposition on a loved one of an unfair, years-long, burden of nursing care,
- to end in death.
- It's a gradual loss of self and most of what's been meaningful.

Before my diagnosis, I hadn't been afraid of death or even of pain, but I was terrified of Alzheimer's; I could not imagine a worse way to die.

Once I'd received the diagnosis, however, my fear … melted. What had seemed terrifying then, now didn't seem frightening at all. I remember thinking even at the neurologist's office: "This will be interesting." Despite losing my orientation riding my bike home from that appointment, I couldn't get over feelings of excitement and curiosity over what this new life would be. My attitude seemed crazy to my rational mind, yet I wasn't so much bothered by the future course as amazed by the wonderful gifts of the present.

Hearing the diagnosis, actually, lifted a great burden. I'd previously been an intellectual, writing, speaking and teaching about complex relationships among economics, politics, consumerism, and so on. But over the several previous years, my writing had become difficult and frustrating; I just couldn't hold all the various factors in my head at the same time. Now I knew why, and it was a relief to let it go. As it turned out, I was tired of being an intellectual. Been there, done that. **Expecting** myself to be the brightest bulb in the room had become a burden that Alzheimer's gave me permission to shed.

The diagnosis freed me immediately from my struggle to be good enough. Never had I been good enough; I always needed to do more. It had been a major downer in my life. But now, I had Alzheimer's! Neither I nor anyone else could expect much of me, anyway. It may seem childish, but the freedom was exhilarating.

Similarly, when I did something stupid, I could let go of the shame and humiliation. I had already told everyone about my diagnosis anyway, so when I forgot someone's name or lost a paper someone had just given me, both of us just shrugged. "Well, what do you expect from me?" I didn't feel the need to judge myself as I did before. I was, after all, doing the best I could.

The end result of that is that I'm easier to be around, a nicer person, my friends tell me. Relationships with family and friends have become more intimate. Relationships with those who'd been strangers bloom. It's a new experience in my life

In fact, I've been happier than at almost any other time in my life.

My weaknesses and limitations have become real gifts.

Conclusion

Let me wrap up. I've shared with you these four stories:

- Satu's story of guilt and pain,
- Margine's story of vulnerability and powerlessness,
- PeeWee's story of weakness and transcendence, and
- My Alzheimer's story of limitation and transformation.

Each required me to face the darkness; each returned a gift that has illuminated parts of that darkness.

Why do I want to share with you about this side of our spirituality: our weakness and vulnerability? Because that's an important part of ourselves that we usually hide from others and, often, from ourselves. We're afraid of our weakness, so we spend much more time trying

to fix it, strengthen it, ignore it or deny it than we do acknowledging it, embracing it or learning from it. We fear bringing our shadow side out into the sunlight.

So we enter our encounters—especially our medical encounters—believing we must project only our positive virtues and hide the darkness. And that works pretty well for the many routine medical interactions where our only task is to administer the technical side of medicine: check an ear and give a prescription for otitis; run a code on the patient whose heart has stopped; or figure out which chemo protocol is best and what the dosages should be. There's no need and sometimes great harm to engage at a deeper level.

But there are also encounters where good medicine requires that we engage the whole person: the *pain* of the child with the earache, the grief of the family whose mother didn't survive the code, the terror of the cancer patient when there is no further treatment. When a friend was dying of cancer, the competent, caring, beloved oncologist who had faithfully shepherded her through the worst of the chemotherapy suddenly disappeared and didn't return calls. He had no more treatment to offer so there was no more use for his expertise. His work was done, he apparently believed, so he walked away, leaving my friend bereft.

We must be able to enter those encounters with our whole selves, including our own weaknesses and vulnerabilities. After suturing a young mother's large leg wound after a car accident, I had to tell her that her young child had not survived. I hugged her, took her hand and we just sat and cried together. Her daughter lying dead on a stretcher in the next room was about the same age as mine, so my grief was real. It wasn't very professional but perhaps the best healing I could have offered under the circumstances.

Your clinical years will offer you countless opportunities to encounter your own weakness and brokenness as you care for the suffering of others. Some mentors and colleagues will push you to hang tough and steel yourself to your patients' vulnerability and pain. But others can teach you how to be receptive to your patients' pain and your own; they can show you how to allow your vulnerability *and* provide good medicine without being swallowed by patients' needs; they can help you through the emotional minefields. Pay attention to them; it takes a while to learn.

Doctors are supposed to be in control; we are supposed to have the answers. But life is out of control and there may be no answers. Let's enter into that darkness even if we have only a little candle that illuminates only a tiny space.