

# Notre Dame Center for Ethics and Religious Values in Business

## Ethical Dimensions of Issues of Access to Medicines and Care<sup>1</sup> April 7-9, 2002

### Closing Remarks: Glenna M. Crooks, Ph.D.

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Before I begin today, I'd like you to give yourselves a hand. You deserve to celebrate your success.

Celebrating is one of the themes that I have for these remarks. We don't often stop to do that, but we need to.

It was an amazing thing to watch you work over the last two days. I have been tracking my emotions as I did. From the outset, I felt grateful. Grateful for being here; grateful for being invited – thank you Father Ollie and Lee and the planning committee – for asking me and allowing me to be here. I was also grateful for the quality of the wisdom emerging from the group, and the commitment and incredible spirit of good will – particularly with all the new faces here, just forming relationships for the first time. I've been to lots of meetings like this and many don't have the spirit of comity I was privileged to observe here.

I was also grateful for something I did *not* see: enthusiasm. Enthusiasm, it seems to me, is what you have at the beginning of a journey. At the beginning you have stars in your eyes and you don't yet clearly know how difficult the task is going to be. What I saw instead was realism and persistence and that bodes well for progress along the way on this journey. And, speaking of persistence, very often at this point in meetings the energy starts to lag. Not here. Right until these final reports, commitment and spirit is evident.

Sometimes I felt afraid, because I could not predict the outcome of the work you were doing. Although I had confidence in the conveners and the processes that they were all about, I know the consequences of our collective failure, if that was to be our end. Naturally, those fears were resolved.

I was also a bit saddened. Next week, I am giving the *Corielle* lecture in Philadelphia. This is an event for a biomedical research institution, and assembled will be the leaders of the community, philanthropists, biomedical scientists, clinicians and others. It is going to be the unveiling of my concept of healing covenants and how they apply to healing the world. This is going to be the inaugural speech. I was sad, because I wish it wasn't me who was speaking, but Bishop Dowling. His remarks were so compelling that if the audience could only hear his remarks, from him, then I wouldn't have to say anything more.

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<sup>1</sup> The focus of this meeting was access to care and medicines for people with HIV/AIDS in the developing world.

But back to fear. I thought, “How am I going to confront that group of Americans next week?” At least at our meeting here at Notre Dame, the *Chatham House Rules* apply to me, too. What I am about to say might not be well-received by the American audience there – or even the Americans here. They might not react well when I say that I think that we, as Americans, are short-sighted. And, we are selfish. And, we are uninformed. We do not know the realities of the world outside our borders. Most of us would never imagine that the 10% of those in the lowest socioeconomic level in our country are better off than 66% of the world’s population. This spring, despite the drought in my region, my township will allow me to water my new garden and I will do that with water that is more pure than what most of the world’s population has to drink. Drinkable water: a luxury for much of the world that we do not appreciate here in this country.

In the remainder of my time, I would like to talk a bit about healing covenants. This subject will not be in the final report, but it will structure how I *think about* the report I’ll be drafting for you. I’ve shared this often in the US with healers, but always in a secular context. This is the first time I’ll do so before faith-based organizations. I am curious about how this group will respond.

I learned only recently that in every culture we know about – because the ancients left us written records, or left us grave artifacts, or are thought to mirror indigenous societies today – that there were two gifts that came from God or, in the polytheistic cultures, the gods: the law and the healing arts.

The law would structure your relationship with another person. If another person harmed you, you turned to a judge and laws for recourse.

But what happened when disease struck you? Disease was something beyond the control of mankind. A “human” lawgiver might have done well enough in settling a property dispute. A community could not be confident that a “human” healer, on their own, could be effective against disease, though. Communities needed another very powerful intervention – a “human” healer who was aligned with God. That’s one of the reasons why in many cases, the healer class and the priest class became one and the same. One person held both roles and held a very, very special place in society.

I don’t think we’ve changed much when it comes to our health. Just because we know how some virus is replicating or where some cancer is metastasizing does not mean we feel any less frightened when disease strikes. Despite our science, there is just as much mystery and just as much terror in disease as there was back then. True, we no longer believe that the evil god *Febris* causes fevers, but that doesn’t mean that a parent sitting up all night with a feverish child is not worried.

What fascinated me as a social scientist was learning that the ancient notions about healing developed as notions of covenant forms of relationships developed. And, that there were two kinds of covenants, both of which were expressed in our common religious traditions and more to our point today, both of which were adopted within our healing oaths. I’d like

to describe them very briefly and talk about what they mean for the healing challenges ahead of us today.

There are covenants of *grant* and covenants of *obligation*. The covenant of *grant* we know best is the one between God and Noah, created after the flood when God says to Noah, "I won't destroy the earth any more by flood." Noah didn't do anything for that – he just *gets* it. It's not until Sinai that God engages humankind in a covenant of *obligation*. Both of these types of covenant framed our medical oaths.

The Oath of Hippocrates is the one that structures healthcare globally and includes both types of covenant. It is a covenant of *obligation*, but only among the members of the healing profession. The oath says, "I will study, and I will learn, and I will teach my fellows, and I will treat his sons as my sons. In some ancient versions of the oath, it even says "we will live together." That's obligation. But then it says "I will *grant* health to the patient." The patient need do nothing in order to have health, in order to have access to healing.

It's not until about the year 1200, when Maimonides, a brilliant Jewish physician, theologian, philosopher, arrives on the scene that this changes. He rewrites the Oath of Hippocrates – it's much more flowery and prayerful – but follows the same structure as other covenants. He adds, "...and may the patient take my prescriptions and follow my advice and avoid the advice of meddling friends and relatives who don't know what they're doing and will probably kill them."

Maimonides took a next step and it was a good one. Where I think he fell short – and we increasingly suffer because of this today – is that he did not include the community in his oath. He did not invite the community into his covenant of obligation. If you are interested in learning more about the best healing covenants have to offer, read Leviticus. It is brilliant. In it is a structure for the role of the patient, the role of the healer and the role of the community. That's what I'd like to suggest that we reach for in the future.

In the *Corielle* lecture, I'm going to call for a reinvigorated covenant at three levels. The first one is a covenant among all healers. I define healers very broadly, and it includes everybody in this room. Anyone who has anything to do with health care or healing is a healer. That includes government bureaucrats, company executives who make choices about employee health care coverage and healthcare marketers. Our societies are more complex today, so the nature of our healers is likewise more complex today. All of us in this room are nothing more than the sophisticated extension of the ancient tribal healers who came before us.

The second one is that we need to call patients into a covenant, and this time it's got to be a covenant of obligation. Covenants of *grant* make people dependent and I don't think we serve people well when we make them dependent. When I was a child the food showed up on the table without my caring about where it came from, and we've done something like that with patients. We've provided them with health care and have expected little – or even nothing – in return. Perhaps now, at least in this country, we are becoming adolescents. Now, we feel independent. We decide whether or not we will take our medicines, for

example. This is like me in high school. I wanted the keys to my dad's car and for him to put the gas in it, but I was not going to tell him where I was going. Adolescence is a normal part of human development, but a horrible place to get stuck. What we as patients need to realize is that we are interdependent with one another, our healers and our communities. This is a message that came through from the Archbishop and continued through all the brilliant speakers at this meeting.

Is interdependence possible for patients? I believe it is. Every patient can do something. Witness what Hillary's (Fyfe, Family Planning Educator, Zambia) programs require a patient do – teaching one other person or talking to their children – something as simple as that is possible for everyone. Scripture even says when Jesus healed, he directed people to go *do* something: Go wash off your eyes, go show yourself to the priest, go home and don't tell anyone. There was an obligation on the part of the healed person to *do* something.

The third one is that whole communities need to be called into this covenant. Too many of our social and economic problems have been laid at the feet of our healers. Healers have been told to solve them. So whether it is violence in American high schools because kids bring guns to school, or unintended pregnancies and low birth weight babies because families do not address sexual behavior, these are matters for the community to address.

I would invite each of you now, since you are all healers, to think about one other healer. Someone in this room perhaps – or someone back home – that you can enter into a relationship with in order to sustain the very tough, tough work of healing that remains. I'd also invite you to think about one patient, if you are seeing patients, with whom you can propose a covenant of obligation. And think about one area in which you can work in your community.

Victor Fuchs, a health economist in this country, said that every nation chooses its own death rate in the choices that it makes for health as opposed to other things. What we've heard in this meeting is something broader than that. The world has chosen a death rate, a suffering rate and a misery index, based on how we have chosen to allocate healthcare resources, how we have allocated global power and wealth and how we have acted equitably – or not – in our work.

Here at the end, I'm going to act like the outsider in Mark's community and reflect a bit about what I saw while I was here and three things that you might consider.

First, this is not just an American issue. This is a developed-world issue. Until Mark's group made its presentation, we focused only on America. We've got to involve the Europeans and other developed nations.

Second, we're not treating a disease; we're treating people and these people have other diseases besides HIV/AIDS. We've mentioned some of them – tuberculosis and malaria, in particular, though there are others – and God forbid, an influenza pandemic anytime now.

Third, then, as my outsider comment, I will express my surprise that, except for grace before meals and Mark's hellfire-and-brimstone speech yesterday, I didn't hear the Divine invoked. Yes, that surprised me. I heard "church" invoked a lot, but "the Divine" was rarely invited into the room. We were rarely reminded of its presence.

This third point led me to think about some private conversations I've had here and Joseph Campbell's distinction between the priest and the shaman. I've already mentioned how the priest class and the healer class were often the same. Whether you are in the ordained religious ministry or not, our cultural, societal perspective is that a healer belongs to a particular kind of priesthood. According to Joseph Campbell, the priest is enculturated by their society and taught society's view of the Divine. This is done at seminaries and by theologians, who transmit what they know and what the culture wants to believe to the next generation. The same thing can be said of priesthood created by medical schools. A certain, structured base of knowledge is transmitted from one generation through a formal medical "priesthood" of teachers. A similar thing could be said of the public health priesthood as well.

The shaman is fundamentally different. The shaman has knowledge from direct personal experience. Shamans experienced personal suffering and conquered their fears – and even death – and returned to share what they learned with others in the community. A physician, in other words, need not die and resurrect. To be a shaman, one must.

I can tell you a story about that. At a meeting of a small group of physicians, I asked everyone to add hobbies to their introductions. When one physician said she ran a funeral home as a hobby, there was –pardon the pun – dead silence. Then, there was nervous laughter from the others and finally someone quipped, "Don't you think that's a conflict of interest?" She said, "No, as a matter of fact, I rather think of it as continuity of care." There she was, right there, a modern healer in the ancient shaman tradition, assuring as shaman's do that the soul returns all the way home to the Divine. This is something that those in a faith-based organization will readily understand, because that has been one of their roles: to stay with the patient during illness and when physical healing is not possible, to remain through the moment of death and in the way of the shaman, assure the soul makes its way back.

What happens to people who confront death as shamans do – and I know some of you have from the stories you've told me – is that the mysteries of life and death are no longer a subject of impersonal, orthodox education, they are a subject of actual, personal experience. You are fundamentally and radically changed. Those fundamental changes, unfortunately, may put you at odds with your church.

For those of you who are clinicians, the seminary of your medical school and the church of your professional society may have told you an ARV cannot be prescribed without CD4 counts. Yet, in the most destitute areas and without laboratory facilities, facing and experiencing death, you acted in shaman tradition and found ways to treat patients anyway. You, and those of religious denominations that laid down rules to follow because

“... theologians teach it and Divine inspiration says so” are at odds with the institutions that trained you.

It is you that I have the biggest heart for right now. I want everyone to encourage and support you because you need it. You are working most directly with disease-weary people, and they you.

For my own part, I am spreading this message in the US and encouraging greater efforts from this country. Others may believe health spending should replace defense budgets, but in my view that debate is not productive and is unnecessary.

We have to deal with the day-to-day habits of the American public. We've got plenty of discretionary income and have decided to spend it: \$100 Billion on fast food, \$24 billion to accessorize cars and \$1 billion on chocolate, alone, just for Valentine's Day. These choices should be more informed by the kind of poverty and devastation that the rest of the world faces.

I think, as well, that we need to engage the Europeans and bring them into this dialogue. The Europeans choose to have price controls on drugs and this is resulting in higher prices in the US. The American public, who would rather spend \$100 billion on fast food, does not want to pay higher prices for drugs. That attitude will lead to less money for innovation and the kind of financial support others here have called for from the pharmaceutical industry.

I want to end on a high note and return to celebration and success. Too often when we get involved in ventures like this we allow the perfect to be the enemy of the good. Let's not allow that to happen here. If we end up only doing good, even if it doesn't look pretty around the edges, we will certainly have done well and far better than if we had done nothing at all.

So, move from one success to another and from one celebration to another. Applaud yourselves and those you work with. Celebrate. I promise you this report just as soon as I can, in as good and honest a shape as your dialog has been today. That's what I'll do for you.

What I'd like you to promise me is that you'll decide right now how you will celebrate the success of the last two days. Will it be a frozen yogurt at the airport on your way out of town? A long nap somewhere? An email to someone you met, wishing them well. Whatever....

I hope that you saw this evolve, emerge, blossom, and succeed. Celebrate that.

Thank you very much.