

If I Could Say Five Things...

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Lifetime Achievement Award

It is a great honour for me to be recognized by my friends and colleagues. Thank you. I am also grateful that some of my family is able to be here today.

When I started in this work, by “this work”, I mean a full time ethics consultant position in a hospital, there was no such position in a Canadian health care facility... the year was 1982. I tell my children there were cars, electricity and running water back then...

This new venture happened because of the Sisters of St. Joseph of Toronto. With all of the changes in health care and health care delivery systems, they saw a need and I was happy to have a job! I crafted a tentative proposal with the assistance of my supervisor and friend Be`la Somfai at Regis, the Jesuit Faculty in the Toronto School of Theology.

I am most grateful for the leadership, imagination and strength of the Sisters of St. Joseph. These women were my mentors and in the early days, my bosses, because they were CEO's – Sister Janet Murray, Sister Margaret Myatt, Sister Mary Zimmerman and Sister Roberta Freeman. I want to acknowledge these Sisters for two reasons: first, because of their incredible legacy and second, I want to begin this reflection from a place of gratitude... the deepest gratitude for all I have been given by others, as I started and navigated this new work.

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Thank you!***

I have received tremendous support and encouragement from my wife, Judith, not only in the “early days”, but, through the many years of my work. I have also enjoyed the love and attention of my son Benjamin (and Erika) and daughters Leah, Anna (and Frank) and Rebecca and three beautiful granddaughters - Georgia, Florence and Evelyn.

Prof. Abbyann Lynch was, and remains for me, a great teacher and mentor. She was already teaching medical residents at St. Michael’s Hospital when I started my work. It is clear to me why so many in our country refer to her as the “grandmother of bioethics”.

I also received great support in what I have called “the early days” from Leo Walsh, Michael Coughlin, Lynda Sullivan, Linda Clarke, the late Tom Daley, Bill Harvey, Francoise Baylis, Jocelyn Downie, Peter Allatt, Christine Harrison, Mary Rowell, Kathy Carlin, Bernard Dickens, the late Benji Freedman and many, many, other friends and colleagues.

The first physician who came to my door at St. Michael’s Hospital in 1982 was Dr. Robert Byrick. At that time he oversaw a critical care unit – his specialty was Anesthesia. He said something like: “I’m not sure what you do, but we have a lot of ethical issues in our critical care work...Maybe you could come by”. I told him I wasn’t sure that I knew what I did either but, I went to the ICU and we worked together there each week until I moved from Toronto to Winnipeg some 15 years later. He was a great mentor. At this time, the ethics consultation work was also evolving at St. Joseph’s Health Centre, Providence Healthcare and Casey House Hospice in Toronto.

On the point about others not being sure about what I do, I have had some interesting experiences. Often when I fly, the person beside me will ask me what I do for a living. I say I work as an ethicist and some have replied: “Oh, you’re the person who puts people to sleep – thinking I said “anesthetist”. Anesthetists put people to sleep with the benefit of drugs – I just have to give a lecture!!

Others have said: “Oh, you do nails and wax – thinking I am an esthetician” – I don’t do nails and wax. Others, still, have said: “Oh, you’re the one who decides when the plug gets pulled” or “You people decide who is going to get cloned”.

Perhaps the most creative was a family member of a patient in our hospital. We met one evening. She attended a care conference the next morning and the charge nurse asked her if she had met with the ethics people and she replied, with great enthusiasm: “Oh yes, I met with the clinical atheists last evening.” A medical resident we know told us that a clinical atheist was someone who didn’t believe in clinics. There is no end to it...

I moved with my family to Winnipeg in 1997 and now I work with my colleagues Pat Murphy, Lydia Shawarsky and Dr. Brian Chaze. Pat Murphy founded the Ethics Service at St. Boniface General Hospital in 1993. Our Ethics Service currently works with 14 health and social service agencies in Winnipeg and rural Manitoba. We have received tremendous support for our work from the Grey Nuns of Manitoba (that’s the Sisters of Charity of Montreal) and the Benedictine Sisters. I want to publicly acknowledge this support and thank them.

So after all this time – almost 30 years, what is one to say? Well, there are five things I would like to speak about...

Here are my five things...

First, I have come to see how *complex* things are... While I had an intimation of this from the outset, it seemed to take a long time for me to really understand and appreciate the complexity and difficulty of many of the issues and concerns that occur on a regular basis both in the therapeutic relationship and in the structures and processes that mediate and “deliver” health care across our country.

These issues now fill bioethics texts, case study collections and bioethics journals. In my ethics consultation work, an enduring concern for me over the years, is whether I have understood the problem or question that has been asked by a patient, their family, care providers, a manager or administrator, or reporter.

This struggle about the complexity and difficulty of this work is not only about knowledge in the more traditional sense of the term, but what I might call deeper human realities. Some things that have come my way are, I believe, imponderable. Other situations expose you to hardship, anxiety, fear, suffering, regret, arrogance, demoralization, moral distress and, what Frederick Bird has called, moral blindness and deafness... the “muted conscience”.¹

My personal learning about the complexity and difficulty of things is this - it is important to know what you don't know and to know when you are in over your head. This learning, I believe, applies to all of us. Know what you don't know – even if it is embarrassing, not good for your career advancement or distressing deep inside. A fitting response to this complexity and these pervasive existential questions, is humility...know what you don't know and know when you are vulnerable. Most of us are vulnerable most of the time, so we need to pause and see the wisdom that resides here.

Second, over many years of work I have thought a great deal about *compromise*. Early in my work, I was mostly preoccupied with finding my way in a new job. I was meeting new people and slowly sorting out how I might contribute to the life of a hospital or long term care facility. As I look back, I am aware of times in the course of a case discussion, conversations with students, an ethics committee meeting, a research ethics board meeting or a discussion with a patient or family where I felt varying degrees of “dis-ease” or discomfort about a decision taken or a proposed course of action.

¹ Frederick Bruce Bird, *The Muted Conscience: Moral Silence and the Practice of Ethics in Business*, (Quorum Books, Westport, Connecticut) 1996.

I am not sure I had the insight at the time to know the import of paying attention to these intimations. I think this has only become clearer with time. I first put a name to this - moral distress/moral residue - in the course of my work with medical students. In what I now call “the blind rectal exam”, a young clinical clerk told me how she found herself in a small examining room with her attending physician and a patient who was blind.

The attending physician was just completing a rectal exam when he said to the patient: “There is one more thing I would like to check.” At the same time he motioned to the young student to do the rectal exam. She told me she felt cornered and trapped and didn’t know what to do because the physician, who asked her to do the rectal exam without the patient’s knowledge, was also evaluating her performance during this particular rotation. She reluctantly performed the rectal exam.

She told me she knew that what she had done was wrong and she deeply regretted her actions. Still, she told me she could not shake the bad feeling. She said it was like washing your hands over and over, but you still feel unclean. It was in this context that I first began to think not only about the meaning of compromise and moral distress, but also, the long term personal consequences of serious compromise.

I tried to find some words to help her understand her experience. It was in this context that I first thought about “moral residue”.

Students teach us many things. Shunryu Suzuki has written that: “In the beginners mind there are many possibilities, but in the expert’s mind there are few”.² I would like to thank this young woman for all she taught me. My only regret is that I do not remember her name. I hope we are all able to see what our students teach us.

² See Shunryu Suzuki, *Zen Mind, Beginner’s Mind*, (Shambhala Publications, Weatherhill) 1973.

I have also experienced serious moral distress working as an ethicist. I first became aware of this when I discovered that a patient had suffered needlessly because I was afraid to speak out and stand up for what, at the time, I believed to be the right course of action. I think I was fearful and wanted to stay on good terms with my work colleagues. Others stronger, or clearer in their thinking, might have stood up – but I didn't know what to do.

This frank admission is not so much about humility, but rather, a desire on my part that all of us doing this work become more aware of this difficult terrain.

I have learned that the opportunities for compromise in ethics consultation are legion. I have also learned, though, that compromise at some level is an inescapable part of this work and often a necessary element in securing a respectful and acceptable decision or outcome in those situations where there is ethical difference. My colleague and friend Francoise Baylis has observed that an ethicist wants to avoid “going along to get along”. The ethicist might expect to compromise, but must continually struggle to not be compromised.

The third thing I wish to touch on is closely related to the challenges and struggles we associate with moral compromise, and that is *courage*. The writer, Tim O'Brien, who has thought a great deal about courage writes: “...it is hard to be brave. It is hard to know what bravery is.”³

I believe Tim O'Brien was correct when he said “...it is hard to be brave”. When we face serious challenges to our integrity or we know deep within ourselves that we are afraid, it is at these times that we feel most vulnerable. On these occasions, one is perhaps tempted to take what we might call “the well oiled road of least resistance” because other options appear to be too difficult, painful, or contrary to our perceived interests.

Our late and much respected colleague, Benjamin Freedman, shortly before his death, wrote an article in the Journal of Clinical Ethics entitled: “Where Are the Heroes of Bioethics?”

³ See Tim O'Brien, *If I Die in a Combat Zone, Box Me Up and Ship Me Home*. (New York: Dell) 1987.

He wrote:

Here is my problem: I don't know of a single case of a bioethicist who has acted as a hero in that role. There is of course much that I don't know, and it is quite possible that there have been such cases. Even so, being a bioethicist and one who trains others in that discipline, the fact that I don't know about them is a problem: for me and my students. And if there indeed have been no such cases, then that is an even bigger problem ...If, they do not exist, we need to know that too, and we need to think about what that might say about us and about the role we play.⁴

I think I know some heroes. Some colleagues have lost their positions, or been threatened with this, for taking a principled stand regarding an important ethical question that arose in the course of their ethics consultation work. Others have stood up to the power and influence of pharmaceutical companies. Others have been shunned in their communities because of opinions they have expressed in the course of doing their work. Some have been told by their clinical colleagues that they were "disloyal" for expressing a different point of view; others have been told: "your writing is seditious".

I do know women and men, many of them care providers, who work quietly with little or no recognition, but whose patients and colleagues know of their loyalty and their gentle and compassionate hearts.

Often, our "heroes" exhibit a quiet steadfastness and an enviable peacefulness. This way of being in the world is not arrogance, but almost always is evidence of a tender heart. It is easy to tell the difference.

Tim O'Brien is right when he says "it is hard to be brave". It has been hard for me and it may be difficult for you as well.

Instead of being paralyzed by fear or uncertainty, though, I have tried to learn from Pema Chodron. She says we must face our fears head on... in her words "lean into our fears". Instead of turning away from what we most fear, she challenges us to:

⁴ Benjamin Freedman, "Where Are the Heroes of Bioethics" *Journal of Clinical Ethics* Volume 7, Number 4 Winter, 1996: 297-299.

“...let go of old grudges, to not avoid people and situations and emotions that make us feel uneasy, to not cling to our fears, our close-mindedness, our hard-heartedness, our hesitation.”⁵

I have learned it is possible to do this, but it can be very difficult.

The fourth thing I would like to touch on is what I call *context*. Here, I am thinking about “seeing what there is to see”. My work over almost three decades has focused on clinical ethics.

A physician friend recently reminded me that the clinical ethicist’s work was about “the particular” and I mostly agreed with his assessment.

Lately though, I have been thinking about the bigger picture. I don’t know if this is because of my age or because of some work we have been involved with in our region regarding patient safety. In my community, these days, many people are thinking about “systems and processes” following the tragic death of Mr. Sinclair in one of our city’s emergencies. Mr. Sinclair was aboriginal and required a wheelchair to move about. He died sitting in the emergency department of one of our hospitals after sitting for over 30 hours. A formal judicial inquiry is pending. It is hard to know what happened. I am thinking about *context* and trying to “see what there is to see”.

I am also more aware of the “bigger picture” because of some new work I am doing with the Public Health Agency of Canada. This work has taken me beyond “the particular” and pushed me to look farther afield. In thinking about this wider *context*, it occurred to me that the bioethics community has sometimes been engaged in ethical debates and discussions that seem remote and distant. I don’t mean to be anti-intellectual when I say this.

I am aware of a community in Northwestern Ontario that is able to send digital diagnostic images “south” as they say - to be read, - or, they are sent to India.

⁵ Pema Chodron, *Taking the Leap: Freeing Ourselves from Old Habits and Fears*, (Shambhala Publications, Boston and London) 2009.

About 50 miles from this community, aboriginal people live in substandard over crowded housing and live with no running water or flush toilets. An Aboriginal family I know, used to secure their drinking water from ditches at the side of the road. I am thinking about *context* and trying to “see what there is to see”.

I am more aware of food security issues, child poverty in a country with our wealth and the growing homeless population, not only in our urban centres, but, increasingly in rural areas as well.

I know people living with developmental disabilities who are afraid to go to the hospital because some care providers don't think anyone would want to live in such a diminished state.

What do we, in the bioethics community, have to say about these questions? I know I have much to learn – I hope we are able to “see what there is to see”.

I am also aware of fine work being done by some colleagues with respect to global ethical challenges. Some of these concerns touch on ethical responses to natural disasters such as Katrina, response to famines, and the availability of anti-retroviral drugs in Africa. I recall a meeting with a physician working at a clinic in Africa and, though drug therapy was a big issue, he mentioned that some days they just needed more face cloths. I am thinking about *context* and trying to “see what there is to see”.

I know I am not wise enough to find my way through most of these challenges. In thinking about our work together in bioethics and this larger question of *context*, I hope we will be able to “see what there is to see...”

The fifth, and final thing, I wish to touch on today has to do with *compassion and kindness*. In the last few years, I have become aware of a change in the consultations that come to our Ethics Service. The “subject matter” is pretty much the same - that is, we get consulted about consent, substitute decision making, end-of-life concerns, ethical difference, etc. What has changed, though,

in many of these consultations, is an expression of concern by patients, clients and families about a lack of basic humanity and decency or, empathy, kindness and compassion. Here are some examples:

“The person who looked after my wife was just mean... there is nothing else to say.”

“I wanted to ask about my father’s medication and no one would make eye contact with me.”

“She wept and wept in Emergency...it seemed like it went on forever. No one came to see her... it was excruciating.”

“The call bell rang and rang and no one came. She ended up going to the bathroom in her bed. When someone finally came, they were angry that she didn’t make her way to the bathroom.”

A recent, troubling example in my work concerned a physician who yelled at the spouse and children of the patient he was looking after. He said that their father and husband should not be in the bed he was in. He was preventing others from receiving care. I couldn’t imagine being the spouse or child of this patient.

Some might see these types of situations as examples of burnout, compassion fatigue, or vicarious traumatization. This may be the case – I am not sure. The inability to express empathy or compassion may be a symptom of a much deeper and worrying concern about the culture of health care. I am not alone in this assessment.

In the United States, for example, the Joint Commission, an independent not-for-profit organization that accredits and certifies more than 16,000 health care

organizations and programs issued a “Sentinel Event Alert” in 2008 entitled *Behaviors that Undermine a Culture of Safety*.⁶

To the best of my knowledge, a “sentinel alert” related to “intimidating and disruptive behaviors” in the health care setting is unprecedented. The behaviors in question include “...overt actions such as verbal outbursts and physical threats, as well as passive activities such as refusing to perform assigned tasks... A survey on intimidation conducted by the Institute for Safe Medication Practices found that 40% of clinicians have kept quiet or remained passive during patient care events rather than question a known intimidator.”

For some care providers, the system is so strained that they feel they can no longer provide ethical care. Others feel caught between the interests of their patients and the pressures of budgets and limited resources. In the face of repeated stress, distress and compromise, some care providers become ethically de-sensitized and diminished. They themselves suffer, patients and families are hurt and colleagues “work around” the difficult circumstances. They may just stay silent or withdraw.

In the face of burnout, compassion fatigue, emotional exhaustion, moral distress and moral residue, is it possible to imagine another possibility? Is it possible to cultivate and nurture a “kinder path”?

I believe it is.

The psychologist Jack Kornfield, writes about “holding the world in kindness”.⁷ For Kornfield, “compassion is our deepest nature.”

Kindness is more than good manners...

⁶ The Joint Commission, Sentinel Event Alert, *Behaviors that Undermine a Culture of Safety*, Issue 40, July 9, 2008.

⁷ See Jack Kornfield, *The Wise Heart: A Guide to the Universal Teachings of Buddhist Psychology*, (New York, NY, Bantam) 2008.

Behind someone's "expression of kindness" to another, one will almost always find that there is understanding...

...someone looks within and finds they are able to demonstrate compassion for another human being who may be fearful, suffering, or at their wits' end.

I think each one of us can make a commitment to explore "a kinder path."

Our workplaces can also make an explicit commitment to patients, clients, residents, families and employees to cultivate and nurture a kinder work environment.

Each of us can be more *attentive* to decisions we make and the relationships we have, not only with patients, clients, residents and family members, but also with one another.

Being more "attentive" or "mindful" means that we are aware of our choices and behaviors from moment-to-moment...

What this means is that I always have a choice about how I relate to others.

I can choose to be kind and communicate empathy and compassion in my interactions with each person I encounter, or, I can respond in ways that create barriers and distance me from the other person.

It is always a choice I make...

Responses that "create barriers and distance me from others" are almost always rooted in fear.

We may have been hurt; we may be angry; we may want revenge; we may want to "teach someone a lesson"; we may be self-protective.

Exploring what I am calling “a kinder path” does not mean we are passive; it does not mean we simply accept bad behavior, wrong doing, or, that we remain silent.

It is quite the opposite. It is moment-to-moment awareness of our choices. Such attentiveness or mindfulness is anything but passive.

The goal of any reflection about ethics is to not only think about the “good”, but to take the necessary steps to help bring about a more kind and humane world...

I hope our bioethics community will “see what there is to see”.

The revered Vietnamese teacher, Thich Nhat Hanh, tells us that “compassion is a verb”. I hope each of us, in our own way, can find a way to nurture and cultivate a kinder path.

Thank you again for this Lifetime Achievement Award.

GCW - 2010