Lecture to First Year Medical Students at UIC Orientation

By Elaine Poggi

My mother's story

My mother was a survivor. She survived the deaths of two husbands, two children, and in the last two years of her life she survived two broken hips. Although she walked with a walker, she still led a very active, independent life. 2 1/2 years ago, she started feeling bad and I immediately flew home to accompany her to see a surgeon at Barnes Jewish Hospital in St. Louis. She was admitted and many tests were done plus a biopsy on a mass in her lower abdomen. Although surgery had been scheduled, the biopsy results showed us that she had Non-Hodgkin's Lymphoma, a cancer that can be cured with chemotherapy instead of surgery. She was then referred to Dr. Smith, an oncologist, who would be her doctor for the next 2 ½ months. Her first chemo treatment compromised her immune system. Although she was put in isolation, she contracted pneumonia and sepsis, was put on a ventilator, and was moved to ICU. After a week she miraculously recovered and was taken off the ventilator. For the next four weeks she was very disoriented. Sometimes she did not know who I was or where she was. She hallucinated, and became physically aggressive with the nurses on occasion. Although her mental state continued to be uncertain, we made the decision to go ahead with the second chemo treatment. On the day of her second treatment, she started to improve mentally. She also began to improve physically, and was soon moved to the rehabilitation institute. She did very well there for almost two weeks, so well that she was about to be released to go home. Unfortunately, she contracted an infection and was moved to the Emergency Room because the doctors were not able to stabilize her blood pressure at the Rehab Center. Three days after she left the Emergency room, she aspirated (choked) during the night, her breathing stopped, her heart stopped, she was resuscitated, put on a ventilator, and sent to ICU. She never again regained consciousness and 40 hours later, she passed away.

My story

I would do anything for my mother. Thus, I dropped everything in Italy to be with her because she needed me. She was 85 years old and I was her only living child. I stayed with her 24 hours a day for the first two weeks. However, I began to feel the strain of not sleeping well and after that, I stayed with her about 12 hours everyday. I accompanied her to all her tests, many times going in the room with her to calm her and reassure her. On occasion, I assisted with the test because she would only allow me to do it. I learned how to care for her physical needs and I tried to help the hours pass for her by singing, talking, and reading to her. I also put up my enlarged underwater photos on the walls to give color and life to the room. I touched her often, holding her hand or rubbing her arms and feet, to let her know that I was close by. I didn't want her to feel alone. I begged the nurses to move her to rooms that had a view of the park, and they were very wonderful to do it. I felt like I was there to protect my mother. She was too sick to tell people what she needed. I was afraid she would not get the special attention that she needed so that she would not fall. I was at her side every time she had to go to the bathroom or I helped her with the bedpan, or changed her diaper. Much of the time she was fed intravenously, but I still tried to feed her a little bit each day. I had asked permission to read her chart, so I read it daily and finally began to understand all the abbreviations and codes that the staff uses. I wrote down my observations of my mother's condition everyday, which I shared with Dr. Smith. I wanted to learn all I could about the disease and treatment because I wanted to take an active part in the decisions. Because I was with her constantly and very close to her, I felt everything she was going through, her pain and all the sticks she received. Sometimes my mother had to be restrained at night so that she would not harm herself. I felt her anguish and I was so sorry. Above all, I was in awe how my mother fought to survive. It was very moving.

I was so involved in taking care of my mother that I had no energy left for my own well-being. I felt so much emotional strain. I was completely alone. My husband and son were in Florence, my daughter in Boston at her university, my nieces and nephews and other relatives and friends lived quite a distance from the hospital. Thus, the hospital caregivers became my family. I depended on them for support. I also relied a great deal on my mother's doctor. I needed to know that someone understood what I was going through.

The importance of the doctor, one doctor

It was very important for me to know who to call for any problem. **Dr. Smith was my mother's attending physician and responsible for her**. Many doctors told me conflicting opinions: to feed her intravenously or not, to continue the chemotherapy treatment or not, to take her off the ventilator in ICU or not. I had to go with one doctor; otherwise, I would have gone crazy. I chose to follow Dr. Smith. He knew the whole story, the history of my mother. He took time to explain his reasons for everything he did and convinced me it was the right thing to do. His reasons made sense to me. He was our rock!

Treat the whole patient and the family

In the film Patch Adams, there is a good message in the final words of Robin Williams. **"You treat a disease – you win, you loose. You treat a person, I guarantee you win no matter what the outcome."** Also Barnes Jewish Hospital seems to have adopted this idea by their publicity in which they say, **"To effectively treat cancer, it is critical to treat not only the disease, but the entire patient including their family."** I'm glad the family is included in this statement. During my mother's two and one-half month stay at BJC, I sometimes felt that I needed the care of her doctor just as much as she did. My mother did not survive the disease, but I did survive the emotional and sometimes heartbreaking moments while caring for her. And it was because of her doctor. Not only did he have the expertise and scientific knowledge to treat the cancer, but he was also kind, caring, and compassionate. These are the elements that I think are indispensable for a doctor to be great in the eyes of the patient and family.

Characteristics of an ideal doctor

I cannot address the scientific requirements for being a great doctor. My hope is that you will become experts in the scientific skills of curing. Without a doubt, competence and expertise are the most respected qualities in a doctor. However, they are not sufficient to fully sustain the patient and family. To be a truly great doctor you must also learn the skills of caring, of communicating, and of showing compassion. Based upon my hospital experience, I would like to point out some of the things Dr. Smith did to communicate his compassion to us, the things that made a difference to me.

Be confident of your competency

You must communicate your competency to the patient and family. Reassure patients and family that you know what you are doing, that you've treated many cases like the case at hand. I felt that Dr. Smith was very competent because he seemed very sure of what he was doing. **He explained everything to me, in a way that I could understand**. I also felt reassured about his competency when other doctors, nurses, and receptionists told me good things about him. **Your reputation does, indeed, follow you.**

Be part of a team

My mother, her doctor, and I were a team. We worked together in a partnership – each trusting the input of the other. My mother needed to help make the decisions, otherwise she would have lost her self-esteem and dignity and she would have felt helpless. As long as she was mentally alert, we three decided things together. When she was no longer able to make her own decisions (which was more than half of her hospital stay), then Dr. Smith and I made them for her.

Every day I prepared my list of observations, questions, and my concerns. Dr. Smith went through my daily list and answered every question I had and took note of every comment and concern. He had a great deal of patience with me and never made me feel like I was wasting his time. He made me feel that my input was just as important if not more important than the other caregivers. Because he took seriously everything I said, I did not feel helpless – I felt like I was participating in trying to save my mother's life. We had to discuss ethical questions such as whether to continue with treatment if she continued to be disoriented. It was a huge weight on my shoulders and **Dr. Smith helped me carry that weight**.

Give hope

Hope was the most important gift that Dr. Smith gave me. **I had hope that my mother could get better, but at the same time I knew anything could happen, because she was 85 years old.** So many doctors had given up hope. They would talk to me about her condition, explaining things in a negative way that would leave me feeling defeated.

Then Dr. Smith would talk to me and explain the same things but with hope. He was realistic about the bad things that could happen, but hopeful that good things could happen, as well. He would build me up and give me courage to continue. I could go home that night and sleep and be ready to help my mother one more day.

One particular moment in which I was very distressed was when my mother was moved to the ICU from the ER. She was not doing well. The doctors in the ICU were giving me negative feelings. One ICU doctor said he knew that Dr. Smith is a very good doctor and really cares for his patients, but that my mother was really sick and he thought that my mother might not make it. And that made me cry. So, I called Dr. Smith and I asked him, "**Should I despair now?"** He said, "**Absolutely not!**". I will bless him forever for those two words of hope. I could have been spending my time and energies just waiting for her to die. Instead, because of her doctor, I used my time and energy to help to increase her chance of survival, to encourage her, to give her the hope to get better. Time passes much better if hope is a part of it. **Please remember this** – if you give hope, the patient or her family can more easily cope with everything. If you paint a dismal picture, it is much, much harder to get through the moment. Because mystery is a constant part of life, we can never be sure how anything will turn out.

I appreciated that Dr. Smith didn't give up on my mother just because she was 85 years old. Perhaps she only had a 30 or 40% chance of survival. He always treated her as if she would be one of the 30 or 40% who would survive. This is important – treat your patient as if she will be one of the lucky ones! He really wanted her to live and tried to do everything possible to cure her. He wanted what was best for my mother, not what was more convenient for him or for me.

Listen to your patient and her family

Listen to the patient and validate her concerns. **Let her know that what she is feeling is not all in her head**. Dr. Smith would enter my mother's room and **totally focus** on her. He looked at her in her eyes, listened to her and never interrupted her. **He made her feel that she was his only patient.** My mom asked if he had many patients like her. He said, "No, you are unique**"**! This answer reassured my mother.

Take time to speak to your patients as human beings

Don't just talk to them about their disease and treatment. Find out something about the patient. **Get to know the person**. I remember when Dr. Smith took a few extra minutes at the end of his visit to talk with my mother and me about other topics not related to my mother's illness. They made my mother and me forget we were there in the hospital. It reminded me that there was life outside the hospital.

He was never in a hurry. He always sat down, as if he were going to stay as long as we needed him to stay. It seems that the doctor stays longer than he really does if he sits down.

Feel the pain of your patient and her family

This involves the willingness to put yourself in someone else's shoes, to take the focus off yourself and to **imagine what it's like to be in someone else's predicament**. It means suffering with the patient or family member, which leads to a unique bond. I felt that Dr. Smith shared in my pain when my mother was so sick in the ICU the first time. I thought she was dying. He comforted me and reassured me that she was stable and still could recover. I didn't want to leave her but he said to go home to sleep. Another moment of sharing disappointment was when he returned after a week's vacation. For some reason he had heard that my mother's mental state had improved, when, indeed, it hadn't. I could feel his disappointment when he found my mother still delirious. It helped me to know another person was sharing that disappointment with me.

Equally, compassion is also feeling and sharing the joy of those little improvements or turning points in an illness. Dr. Smith and I were both joyful when my mother, after about a month of mental absence, actually did returned to her normal mental state. We rejoiced when she was taken off the ventilator and moved out of ICU**.** Other joyful days were when my mother was improving at the rehab. She was joking with the therapists, her hearing was back to normal after a three-week period of hearing very little, she was off the TPN and eating, and she was enjoying her visitors.

Be an advocate of your patient

I felt that Dr. Smith was on my mother's side. I knew that he would fight for her well-being. He argued for her – he had problems with the administration finding a nurse from another floor (she was still on the surgery floor) to give her the first chemo treatment, so he personally came with his nurse to give her the chemo. He stayed the whole hour. He reassured me that after she was home he would make sure that she would be brought to BJC if something happened. **He gave me the confidence that he would solve any problem that could arise.**

Encourage your patient and her family

I think a doctor has the power to strengthen his patients' will to live. The way in which the doctor sees the patient sometimes becomes the way in which the patient sees herself. If a doctor expects his patient to get better, the patient picks up on this and it affects her ability to get well. My mother kept asking me if I really thought she might get better. I told her always that Dr. Smith said that chemo can cure Non-Hodgkin's Lymphoma and there was indeed a chance that she could recover.

Dr. Smith also encouraged me. One day I was a bit down and I asked him what else could I do to help my mother. He said that he applauded me for what I was doing for my mother, that very few family members do for their loved ones what I was doing for my mother.

Be available

I knew **I could call on him anytime**, although I never called him at night. He said often to me "you should have called me. I was expecting a call from you." He always said, "if you need me, you know where to find me". I did call his office on a number of occasions. His receptionists always got me through to him somehow. If he was not available, then I talked to his nurse. Often he came to see my mother early in the morning, and if he missed me, he would try to come back in the evening so he could talk to me. The last days of my mother's life, he gave me his beeper and cell phone number and said to call him (he was out of town).

Tell of your experiences

When doctors tell their own stories, it helps. Dr. Smith told my mother about how his grandmother had cancer and after two chemo treatments, said that was enough, that she wanted to stop. **It is very good to draw upon your own experiences, to show us that you also are human**!

Be a refuge for your patient

You can lift the loneliness of the patient and family. This makes all the difference- that someone else knows, that someone else cares. Sometimes your doctor is the only person you can talk honestly to, who understands all the experiences you are going through. Your doctor is a friend, someone you can connect to and someone who understands you. He is there for the patient – vigilant and trustworthy. A doctor offers his care and companionship, his willingness to face the unknown with the patient.

Dr. Smith was my refuge on the last day of my mother's life even though he was out of town and we communicated by phone. I felt so alone and I felt that I had to make some kind of decision. I thought she would die very soon and I didn't know if I should take her off the medication that was keeping her blood pressure elevated. He said do not do anything, don't make any decisions, let nature take its course. She wasn't suffering. I was the one suffering. I had done everything I could for her and now I should take care of myself and rest. He called back the next morning and finally said there was nothing more we could do, to let her go.

Be humble

Sometimes, patients and their families might think of you as God. Those are big shoes to fill. I like to think of it as if you are a vessel through which God is working. I think He uses doctors to heal and to comfort those who suffer.

A great doctor gives credit to the people who support him and work with him. When I told Dr. Smith that I thought he was a great doctor, he said that if he is a great doctor, it is because he has great people supporting him. He said his staff is the best he's ever had.

Look beyond the behavior of your difficult patients

Please forgive your patients for some of the things that they will do. Underneath even the most annoying behavior is a frustrated or sick person who is crying out for compassion. **Try to look past the outer person to see the soul - the precious life within the body**. **Every person's soul is worthy of compassion, no matter how young or old, how rich or poor, his or her nationality or religion.** To be compassionate, you must open your heart to your patients and feel love for them as human beings.

My mother was a very difficult patient on occasion. Sometimes she would try to bite the nurses or specialists that came to treat her. I think she even tried to punch a few. I told the staff that she would never do something like that if she were in her right mind. She just didn't know what she was doing.

Be aware that your facial expressions, mannerisms, and words make a difference to the patient and her family

We notice every facial expression, we search your face for the reassurance that you really care and for any sign of hope. If you show us that you are worried, then we will worry more. **We listen to every word you say and then think about it all day**. When the surgery team of doctors spoke among themselves about my mother, at the end of her bed, she felt feelings of anxiety and fear. Because she couldn't hear what they were saying, she thought they were saying bad things about her. I could see the fear in her eyes. These doctors had no idea that their words were affecting her in this way. I don't think it is a good idea for a medical team to discuss the patient's condition in front of the patient. They should do it outside of the room.

Touch the patient

Do not be afraid to touch your patient. Get close to her, touch her arm, hold her hand, and give her a hug if she asks you to. My mother asked for a hug from two different doctors. One hesitated, the other gave it freely.

The night before my mother died, I decided to stay by her side because I thought she might die anytime and I didn't want her to die alone, after all we had been through together. I sobbed by her side many hours. Her nurse came over to me and hugged me and cried with me. I said, "How can you cry with me, you don't even know me, you have never seen me before?" She said, "The day I can't cry with another human being is the day I should stop being a nurse." Try to surround yourselves with this type of nurse. And finally, about two hours before my mother died, Dr. Smith's colleague came in to check on her. He gave me a huge hug and I felt his love and compassion flow into me. I will never, ever forget that hug.

What a doctor should not do

Never make family feel as if they are in the way.

Sometimes family are frightened and feel helpless. My mother was moved to the ER at 10 pm. It took me quite a while to get through the registration so when I finally joined my mother, I asked to speak to the doctor in charge of her. I was very afraid for my mother and I wanted to explain what had happened and a bit of her history. I thought I was a valuable resource to him. Instead, he interrupted me to say that as long as I was talking to him, he couldn't help my mother. In other words, I was wasting his time. I already felt bad, and that just made me feel worse. Not only did he cut me off and ignore me, but also this caused a delay in her diagnosis.

Be very, very careful what you write in your patient's chart.

Some families read the chart! When my mother was moved to the ER from the Rehab, she was very sick. In the ER she was lying on a hard stretcher-like bed for about 15 hours before she was moved to the ICU. I left her side for just a few hours to catch some sleep. While I was gone, a doctor, I believe she was a resident, talked to my mother. I never did meet this doctor. She wrote 5 pages about my mother at 5:30 am. She had never seen my mother previously, she didn't know her medical history, or what she had already been through. The following are some of her comments:

"Patient is very concerned about undergoing CHOP again. She does not want to go through it again but feels FORCED to do so by her daughter primarily and Dr. Smith secondarily… Patient is also not sure she wants to be Full Code – she doesn't want to be intubated again, however her daughter has talked her into being FC.

Patient is on antidepressant, which is unlikely to help given persistent source of unhappiness. Quality of life issues need to be discussed and Dr. Smith needs to give an approximate, realistic prognosis for this patient. She appears to be dominated by her daughter in an unhealthy relationship."

This was my most negative experience of the entire two and one half months.

My mother was scared, very sick, and a bit delirious at this point. I can image that she might have expressed her fears. Only two days before this, she was well enough to go home, except that she needed to have another chemo treatment. If the resident had concerns that my mother was being abused, she should have talked to Dr. Smith and me directly. She should never have written in a chart such value statements and criticisms of another doctor. She knew nothing. If she thought something was wrong, there were other channels for her to follow. **I was very disturbed to think that all the doctors, nurses, and caregivers for the last 6 days of her life, read the chart** and thought that I had an unhealthy relationship with my mother and that her doctor needed to be more realistic. Unfortunately, I didn't read the chart until two days before my mother died. Dr. Smith was trying to protect me. He didn't want me to read the chart because he knew I would be upset. In fact, when I finally got him to sign the permission form, I read it and I could hardly breath, I was so upset. That evening I cried all the way driving to my niece's home and I cried on her shoulder for an hour. I went to bed but four hours later I got the call from the hospital that my mother had aspirated, stopped breathing, was resuscitated, intubated, and moved to ICU. She never regained consciousness. Thus, I was never able to resolve this with her. I am just thankful that I have other memories of my mother's gratitude and love. Dr. Smith did file a complaint and I believe it was explained to the resident the gravity of her words in the chart. To let you know how important it is to avoid this mistake, I want to tell you what happened at my lecture to the first year medical students of Washington University in St. Louis last year. The head of the ICU program was beside me while I spoke. When I told this part of my mother's story, he was furious. He said that if he had known this, he would have thrown the resident out of the program. Please be very careful!

Do not contradict a doctor who knows more than you do about the patient and her disease.

There were a number of doctors who told me that oncologists tend to be aggressive with their treatments and they don't look at the whole patient and how they are suffering. They try to cure the cancer but don't see the other problems of the patient. These doctors told me that I should think about this and do what is best for my mother. But I knew exactly what was going on. I had asked hundreds of questions! I knew if she weren't treated with the chemo, then she would die. The hope of living would be gone. I didn't want to just let her die, especially since there was hope that she could recover from this type of cancer. <u>And she was fighting so hard to live.</u>

Do not assume that your patient is not aware, that she can't hear you.

When my mother was in the ICU the first time, the ICU doctor said to me in front of my mother (who was hopefully not able to understand) that he would sign with me to take her off everything to let her die. He didn't expect her to recover from her multiple problems. I didn't like that. First, he should not have said it in front of my mother. Secondly, I just didn't feel like it was her time. Thirdly, I had not gotten this idea from her doctor. In fact, he didn't like that this doctor was saying these things to the daughter of his patient. They were too negative. Just because a patient has cancer, it doesn't mean she is doomed. My mother did recover four days later. She was taken off the ventilator and sent out of the ICU.

Don't try to predict death.

Don't give a time that you expect the patient to die. Be vague - or just say that you don't know. You can say maybe soon, maybe not yet. Be open to the possibility of the surprising, the mysterious. The human body is incredible. My mother had courage, strength, faith, and the will to live. My mother survived pneumonia, sepsis, and the ventilator in the ICU. Not many people thought she would survive all that but she did!

Don't say it is time to get the patient's affairs in order. That is giving up. A doctor, who I had never seen before, told me to do that because she had about a 40 % chance of dying! How in the world do you determine a percentage? That takes away hope.

How will you be rewarded if you care?

Well, you may not be rewarded. In medical school you will be graded on how well you can cure a disease or repair a broken bone, not on how well you communicate with a patient. You will be rewarded for your skills of curing, not caring. However, there are signs of hope. The fact that I am here today, speaking to you, shows that at least this school of medicine is giving importance to the human side of medicine.

You may never know how important you are to your patients and their families. Some people do not know how to express these feelings of gratitude. **But I guarantee you, if you have touched them on the most profound level, if you have communicated with their soul, then they will carry you in their hearts their whole lives.** You will be rewarded because you have made a difference in their lives. I have talked to many people about their experiences with great doctors. As they tell their stories, they get that same look in their eyes – **a look of affection, of admiration, of adoration, and of love.**

Epilogue

Never underestimate the effect that your kindness can have on your patient or their family. Even though my mother died, I have been empowered by how I handled her death. I feel that all the right decisions were made, that she was given a chance to survive, and it was done with respect. Her death was not a failure of her doctor or me. Her death was the natural process of life.

In response to Dr. Smith's kindness, two extraordinary activities have developed since my mother's death. One activity has been the creation of **The Foundation for Photo/Art in Hospitals**. Along with my mother I experienced endless hours of loneliness, staring at sterile, white hospital walls. Through my Foundation, I place my colorful, soothing photographs of nature and beautiful places from around the world in hospitals. My wish is to give hope and comfort to patients and their families, visitors, and caregivers, to help soften the often stressful hospital experience.

The other activity is speaking to medical students and doctors as I have done today and in the past. I have shared with you my mother's story and the importance that her doctor had for both of us. I have pointed out how he gave us hope, how he felt our pain, how he was our refuge. I hope I have shown the importance of learning the skills of caring, of communicating, and of showing compassion not only to the patient, but also to the family. My wish is that what I have shared with you will influence you in some small way to be the best you can be - to make not only good medical decisions but also compassionate decisions, always keeping in mind both the physical needs and the emotional needs of your patients and their families.