

Initial Experiences in Medical Ethics
An Exploration of Personal Opinion and Thought



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-DCW-

Project Abstract

College Scholars Project
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Within the realm of health care provision, there are several circumstances which are easily categorized as ethical in nature. Examples include abortion, euthanasia, and allocation of donor organs. These instances are indeed encountered by physicians on a somewhat regular basis. However, there are several more subtle ethical circumstances which are encountered with just as much frequency, if not more. Many of these cases revolve around issues of patient/physician/staff communication and understanding. Falling in this category are issues of truth-telling, conservation and destruction of hope, respect for autonomy, compassion expression, and competency determination, as well as several others that are not as easily labeled. With regard to these areas of the patient/physician relationship, it seems that the environment of medicine has the capability to catalyze changes in the communication ability, style, and effectiveness of the physician. As a student facing a career as a physician, a case study of my own ethical catalysis with regard to communication ethics seems especially accessible to research, as well as especially interesting to me. The following is a collection of encountered cases, interview results, and personal observations. Each involves personal experiences, chronological accounts of patient feelings, and most importantly - personal viewpoints based on my experiences to date. Overall, this project involves capturing how I feel at this point about a multitude of distinct cases, continuing to account for thoughts over the next four to seven years of training and personal growth, and ultimately evaluating any changes in philosophy brought about by the process of becoming a physician. It is to be an open ended project, and a single conclusion may not follow for years.

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Introduction:

I struggled for some time with my ultimate decision to become a physician. It has always seemed to me that being a physician is a lifestyle rather than just a profession. Most physicians do not punch a card and work an eight hour day - they are a physician 24 hours a day; they become the doctor. This fact was indeed a component of my initial anxiety about attending medical school and becoming a physician. Questions like " Will I resent the personal infringement of medicine? Will I dislike the long hours? Will I become disgruntled by an extended amount of higher education?" were frequent in my thoughts during the time when I was making decisions about my future. One question, however, was far more prominent in my thoughts, and certainly more difficult for me to answer. Would I be able to effectively treat and handle the disease and illness of other people, and maintain a humanitarian and ethically sound approach to medicine? I feared (and still fear) that total immersion in the medical environment might somehow turn me into strictly a scientist rather than a physician, a mechanic with no counselling skills. Indeed this is sometimes, if not often the case. The writings of those currently in medical school or fresh from its exit doors warrant such fears. It has been written that " Essentially, modern medical training requires doctors to enure themselves against human empathy on order to prepare themselves for their calling, a condition that leaves them less prepared to fulfill it." (1) So, although not a given, it is possible for the study of medicine to cloud, if not strip away beneficial character traits within the physician in training. What a disheartening thought! Empathy, compassion, and quality communication seem to me to be the very components of medical treatment that are most appreciated by the patients, as well as most critical in upholding contentment and faith in medicine as a whole. If practicing as a physician meant becoming thick-skinned to the concerns of patients and shedding the ability to express empathy, I was not sure if I wanted to devote my professional future to

medicine. I did, however, eventually make the decision to pursue an M.D. degree with 100% of my ability, while guarding against the possibility of unwanted changes in my personality. Perhaps I felt compelled to beat the system. Maybe I simply decided that I was somehow immune to the possible loss of empathy and emotion. Or, perhaps I subconsciously decided that approaching medicine strictly as a scientist had more utility, even if void of compassion, than not being a physician at all. I do not know, but for whatever reason, after much deliberation, I felt compelled to be a physician....and a listener.

I have continued over the past two years to see first hand continued evidence of the dehumanizing aspect of a life spent dealing intensely with the biology of illness. I have seen and heard the stories of the changes individuals have gone through. I have read of what it can sometimes mean to become a physician. One Johns Hopkins School of Medicine graduate has written that "Most who choose medicine as a career do so with the intention of one day caring for sick people, but the heavy emphasis on molecular science from the very outset of medical school without any humanizing patient-care experiences to balance it begins to drive a wedge between the physician-to-be and his or her future patients." (2) Although I have yet to personally experience the rigors of medical school and experience the environment of such study, I have definitely seen evidence of the trend depicted by this doctor.

I also have seen the disillusionment individuals have with what I often call the "technician, M.D.". I once spent the day as a student observer in a particular hospital unit. In an effort to make myself feel more comfortable and unrestricted, I light-heartedly announced to the charge nurse and her nursing staff, "Let me know where I can and cannot go. I'd hate to do something to make you kick me out of here." The charge nurse replied, "We won't kick you out unless you start acting like a doctor." Smiles followed from all of the nurses. "I hope you don't ever become that way," she said. I must have appeared a bit perplexed by this statement because after a brief pause, the nurse

elaborated, "You know...caught up in nothing but being the doctor." I let the conversation fade from here, but my thoughts dwelled on those words for some time. Perhaps that particular nurse was making reference to the stoic, fighter-pilot demeanor that some physicians develop. It may be that she was commenting on the style medicine where impatience and frustration dominate patient contact. Or, it is possible that her statements were nothing more than a reflection of personal power struggles she feels with physicians. Regardless, this nurse clearly felt that there was something for me to guard against in my future.

It has been experiences like this and literature like that quoted, as well as a personal philosophy on what a physician should be, that have been the motivation behind the stories and experiences that follow. I decided that the most accurate and valid way to investigate the catalyzing effects of a career in medicine would be an extended case study of my own experience. The first step of which is an account of my opinions and thoughts. I began to place myself in environments where I would have the opportunity to witness an array of treatments, personalities, and circumstances. I talked with patients, interviewed physicians, read the opinions of others, and spent time with hospital staff. What follows are some of the more memorable stories and experiences I discovered. Most revolve around the complexities of communication, the relationships between health care workers and patients, and simply what is best, if not morally required, to do in given situations. It is my intent to both capture how I feel about a multitude of ethical issues and define my own personal viewpoints at this early stage in my development as a physician. Over the next several years, I will be able to observe any changes from what I assume will eventually appear as the rather naive opinions and thoughts captured in the following pages. Maybe the fact that I have spent a good deal of time thinking about and witnessing these emotional scenarios will serve to provide a more hearty shield against the aspects of medical school of which I have grown so leery. I hope so.

As the following cases are read, it is important to keep in mind that my experiences have been slightly altered in some cases to protect the identity of those involved. Some cases take the form of a narrative, others simple description. In every case however, my personal thoughts are included, especially with respect to the fundamental issue raised by each experience. I am very much aware that my exposure to medicine, sickness, and death is extremely limited at this point. The following pages are the gut responses I have had to the people I've talked to and met. They are the opinions of one individual interested in medicine, but void of the knowledge and responsibility of a physician. Perhaps such knowledge and responsibility - the "moral heat of the kitchen," as one physician told me - is the stained glass through which medicine is viewed differently. I suppose I will know in five years. My thanks to those who devoted their time, thoughts, and stories. I plan on maintaining a willingness to listen, and change my thoughts in accordance with what I hear.

One Mouth, Two Ears - In That Proportion

Surgery is unlike any other environment I have experienced. Everyone dressed the same, with only a name tag, eyes, and build varying. Everything is scrupulously clean, well-lit, and very organized. The patient is brought in on a stretcher, almost always awake. Sometimes the patient is silent, other times the individual is curious and questioning, and almost always the patient seems nervous. Once this person is put to sleep, the visual of surgery becomes a bit more shocking - or at least it was for me the first time I witnessed it. A person who only seconds earlier was most likely in control of his or her body and able to hear and see the surroundings now lies unresponsive and at the mercy of strangers. For a good deal of the techniques, the patient has his or her gown removed and is positioned according to the procedure. It is during this positioning that the patient seems to transform from a person into the fabric which the surgeon will cut and sew. Indeed, it becomes easy to gaze into a draped, exposed hip joint or visceral cavity and forget that what lies in front of you is a person. This is especially true when this type of thing is seen with the frequency and repetition of a surgical nurse, technician or surgeon.

I fully understand the sterile, obsessively organized environment of the hospital OR; I accept the lab-like approach to viably completing the procedure intended, as this is the goal when performing surgery. I understand the light-hearted conversation and often times up-beat music that can be heard in attempts to reduce stress. I know that I would appreciate any reasonable method of stress reduction were I the surgeon. What I do have a hard time accepting is when the routine of surgery becomes so methodical and mechanical that the individuals involved in performing the procedure lose sight of the people they are treating; when it is forgotten that although under general anesthetic, nonresponsive, and at the mercy of the surgeon's hands, these people deserve the same

amount of respect as when they are conscious. Perhaps letting go of the awareness that it is a person beneath the scalpel is a safeguard that allows the surgeon to maximize their effectiveness - comparable to the mental exercises used by pilots that keep them from cracking under pressure. If so, this approach has utility in the OR and is intended to better the outcome for the patient. Yet, I cannot help but feel that sometimes the transformation from person to "surgical case" spills over into an area of disrespect.

I remember one day when I was particularly appalled by what I felt was an unnecessary OR conversation:

"Bring him on in Derek," requested a voice from within the OR.

I brought in the patient on his Stryker bed and parked him along side the OR table. He was a middle-aged man, I'd say in his late 50's. He was having back surgery that day. This man was the quiet kind, patiently waiting for the next step in completing the whole process.

"Alright Mr. J, slide on over towards me if you can. The table may feel a little cold," said the circulator.

Mr. J silently complied, and I removed the Stryker bed from the room. The anesthesiologist prepared to do his magic with a drug wittingly referred to as "the milk of amnesia." Two or three minutes later, Mr. J lay silently on the table.

"Let's go ahead and position him," stated a nurse as she looked towards me and another male orderly in the room. The usual process began: The patient was freed from his gown and blanket. The dead weight of his body was then shifted into the appropriate position and padded for protection. He began his metamorphosis.

What I thought was a rather sudden shift in the general conversation of the OR then occurred as the nurse anesthesiologist said, "This man is an admitted homosexual, and it appears he took a liking to someone in this room just prior to his little nap."

Mr. J had a clearly visible erection.

"You're closest to him!" someone said; laughter followed.

"I just don't understand these people," a pair of eyes added from the other side of the room.

This began an open-forum for sorts and the topic of homosexuality in general, and eventually the always controversial and opinion-riddled topic of gays and AIDS came up.

An orderly, who in my opinion was personally threatened by the possibility of being responsible for Mr. J's erection, vehemently exclaimed "AIDS is God's way of showing these faggots what's right!"

"I'm going to check on things next door, " I said.

At this point I felt compelled to leave that particular room, and I carried on with my duties elsewhere. I cannot say that at that moment I felt anger. It was more a mesh of disappointment and confusion. Surely it is possible that the nurse anesthetist's comments on Mr. J's sexual preference were intended to relay to all in the room a subtle warning, a message to enhance precautionary measures. Her intent may have been to bring everyone in the OR closer together, so as to maximize self protection and effectiveness of treatment. Was it an uncalled for breach of confidentiality? Perhaps, but what disturbed me the most that day were the unnecessary condemnations of Mr. J's lifestyle. Although not everyone in the OR participated in the conversation, a large enough number took part that, quite frankly, it scared me. What if Mr. J were a loved one of mine? a brother? What if I was Mr. J?

The encompassing ethical question embodied by this experience becomes: Is it acceptable for comments concerning lifestyle or personal opinion to be allowed in a surgery environment, given that the patient is at that moment unaware of any potentially, if not blatantly, upsetting comments? Clearly the key that unlocked the gross and unnecessary display of what I see as biting personal opinion was the fact that Mr. J supposedly could not hear these comments and could not respond. After only a brief amount of reflection on Mr. J's case, I have decided that I object to the allowance of such conversations in the OR. The patient and patient's family would most likely be offended to

know of such remarks, especially in a professional environment like a hospital. It is also not impossible that in some instances, comments will be heard and later recalled by the patient. Certainly this is unacceptable. Even those who might somehow justify the acceptability of statements like those made during Mr. J's surgery would most likely agree that if Mr. J could hear throughout surgery, professionalism alone would warrant the restraint from these expressions. This possibly subconscious knowledge that offensive statements have no place in a clinical environment is evidenced by the fact that no such comments were made until Mr. J. was out, supposedly (and most likely) ceasing his ability to hear. This seems like blatant professional misconduct. In my opinion, it taints the respectability of the individuals who contributed to the conversation. I however do not object to such comments for this reason alone. Clearly, similar comments could and are made in hospital break rooms, on the way home from work, and to others outside the arena of medicine. The comments made in the OR, in the presence of the anesthetized patient, have no more harmful effect than those said by anyone, anywhere, supposing that the anaesthetized patient never hears the comments. It is therefore, on the basis of utility that I object to derogatory OR comments. Most likely, such remarks do not heighten the effectiveness of treatment and serve no useful purpose. As cliché as it may be, my thoughts echo the lecture heard by most of us as children, "If you cannot say anything nice, don't say anything at all."

There are those who might argue that comments such as the ones made in the care of Mr. J are usually lighthearted and indeed help lighten the mood in the OR, thereby making surgery a more relaxed and productive environment. I refute this simply because there are several ways to manipulate the stress of a given surgery environment that do not feel so disrespectful to the individual being treated. A good example is the already mentioned frequency of either up-beat or soothing music throughout a surgical procedure.

I feel as though Mr. J was done an injustice that day. I witnessed first hand how he was made to feel confident that he was in good hands, only to have his lifestyle openly

ridiculed while he was anesthetized. It is interesting to note that the inappropriateness of the comments made during Mr. J's surgery are inflated in hindsight as it was revealed that he had a penile implant, and did not exhibit an erection at all.

One of the most interesting aspects of my experience with the Mr. J case was the fact that the freely expressed opinions on homosexuality were triggered by misunderstood interpretations of Mr. J's physical appearance. What happened to Mr. J is indeed similar to an experience I had with another patient in surgery for this very reason. The misunderstanding, however, was one of history and personality rather than anything physical. The experience was very telling of how an uninformed hospital worker will form personal opinions of a patient based solely on the limited exposure they have to the person. Often times these employees do not know the history, the story, the reason - and it seems to me that the result is a subtle barrier to the expression and existence of compassion.

I remember one exemplary experience quite clearly. It was not unlike any other weekend shift I had worked before. The same routine on my part and on the part of the nursing staff, only a different face staring up from the hospital bed.

"Derek, run up to the North Wing, room 817, and pick up Mrs. Reds. Try to move her over to a Stryker bed before you bring her down. It will be easier to move her once she is down here in the OR," said the nurse.

I suited up in my white lab coat and went on my way, blending in with the other white coats that weaved about the hallways.

I arrived at room 817, "Good morning Mrs. Reds, my name is Derek. I'll be taking you down to surgery this morning."

"Fine, Fine.....Let's get this goddamn thing over with."

"I need to ask you a few questions before we get going. Do you have any false te-"

"No!" She immediately responded before I could finish asking her about her teeth.

"O.K., are you wearing any jewelry?"

"No, I am not. I've already answered all of these questions; can we not just get started? I didn't even want to come here!" she exclaimed.

I finished my questions, and she answered each one with just enough compliance to relieve her of the label of a rebellious patient.

"Do you have any family here with you today?"

"No," she sharply answered. "Are you going to try to move me over to that gurney, because you're damn crazy if you think I can move at all with my leg in this kind of shape? You're going to have to take me down on this bed here, whether you want to or not, young man."

I found my patience being tried with this individual. But, I accepted her requests and went ahead and took her to surgery on her hospital bed, disregarding the nurse's instructions. The relatively short journey included several unavoidable bumps, such as one might expect when rolling a bed into and out of elevators. Each of these bumps was followed by a swift cussing of my ability as a driver and a clear expression of her supposed lack of attentiveness on my part. I felt like asking this patient to keep her mouth shut and show some acceptance of the fact that injury and surgery are not enjoyable for anyone.

"Everyone who has a leg in your kind of shape is going to be uncomfortable, regardless of our efforts Mrs. Reds," I wanted to preach to her. I felt, however, that a statement like that would only deepen her frustration and worsen her attitude. So, I allowed Mrs. Reds's comments to slide off my back as I secretly and angrily tried to determine how an individual could be so down right mean. By the time I got to the OR, I was exhausted with Mrs. Reds. I locked her bed down, and I left her with the nurse as I prepared to go into the OR suite.

In the OR, Mrs. Reds began to make demands. "Please move my IV into the back of my other hand, it is hurting in this hand."

"Mrs. Reds, you will be asleep soon, and you will not be feeling anything at all. It will just cause you more pain if we try to start a new line," said the attending nurse.

Mrs. Reds sighed deeply, and was gingerly moved over to the operating table after this. Her disgust with the whole experience was plastered all over her face.

"Don't lean on the table that way!" she said as a nurse made some necessary adjustments. "Can't you see it hurts when you do that?"

"I'm sorry ma'am, but we have to do a few little things before you are put out to insure that you will be O.K."

"I'm tired of being told that this and that has to be done- just put me to sleep and let's start.....please!" replied Mrs. Reds.

Shortly thereafter, Mrs. Reds got her wish, and the frustration on her face vanished as she quietly lay on the table. Within the OR, everyone began to express their opinions of this seemingly dispicable personality. The mood was one of definite frustration, impatience, and disgust. Strangely enough, as the wrinkles of anger left Mrs. Reds's face, they appeared on the faces of those in the OR.

"What a hard-nose bitch!" said one individual.

"This woman is full of all kinds of mean," said another.

It was during this conversation that I also found myself being resentful of Mrs. Reds. All of us were there to help her, and the only response from Mrs. Reds was one of criticism and complaint. Was she truly as upset with the care she was receiving as it seemed? If so, I quickly concluded that Mrs. Reds had no foresight; she could not see the beneficence of strangers that was aimed in her direction. Or perhaps she could, in which case she was simply mean. Apparently everyone else in the OR felt the same way, as the comments of disapproval for Mrs. Reds's personality continued.

The surgeon walked in during the volley of complaints about Mrs. Reds. He did not seem surprised at all to see the environment Mrs. Reds had managed to produce prior to being put to sleep. He listened briefly to the various comments about this difficult patient, and then intervened.

"In Mrs. Reds's defense, you all should know that just three days ago she travelled here from New England to be with her daughter through the holidays. Her daughter has metastatic breast cancer, is a single mother of a toddler, and needed some help due to her chemo-therapy. Mrs. Reds is a cancer survivor herself, and was holding her grandchild yesterday evening when she slipped and fell. In her attempts to protect the child, she crushed her own leg pretty bad. Now she is in a strange city, having leg surgery she cannot afford, and her daughter is at home without the necessary help she needs. It's a rather sad situation."

Something interesting then happened. An almost immediate transformation occurred in both the grimaced faces and frustrated demeanors of everyone in the OR, including me. What took the surgeon only 10 or 15 seconds to share with us had allowed for heightened patience and understanding, rather than frustration. It was as though this brief synopsis of Mrs. Reds's reason for being in the OR that morning made her belligerence acceptable. Indeed, I found it quite easy to be more understanding.

Although Mrs. Reds will never know it, she made a lasting impression on me. She opened my eyes to a fact put most eloquently by the author of an anonymous letter found at an outpatient clinic: "Never lose sight of the people behind your charts. Each chart represents a person - with feelings, a history, a life - whom you have the power to touch for one day by your words and actions. Tomorrow, it may be your loved one - your relative or neighbor - who turns into a case number, a green card, a name to be marked off with a yellow marker as done for the day." (3) Mrs. Reds was well on her way to being another difficult patient whose case was speedily completed and face soon, and willingly, forgotten. The empathy almost demanded by her story saved her from this fate however. It truly makes me wonder, how many other patients would be treated with a pat on the back or a warm smile, rather than mere tolerance if a few seconds were spent listening to the story? Furthermore, how much more compassionate would the encounters with hospital staff be if these people would realize that everyone has a story, even if the details

are not known? Granted, there are individuals who can be extremely mean when suddenly slapped with the label of "patient." But, a hospital environment is intimidating; it is a generally unfamiliar setting and the resultant anxiety, combined with the anxiety of simply being sick, often manifests itself as anger or short-temperance. I feel that the expressions of patients' disgust would be best handled if it could be constantly remembered that there is a reason for the disgust, reasons most of us would use to justify our own anger in a similar situation.

Patients like Mrs. Reds are disconcerting. There are some people who are ill-disposed and unappreciative no matter what; they are simply have that type of demeanor. These are the type of people who demand tolerance in combination with understanding because they are simply rude and ill-mannered. Maybe one day I will have a better understanding of the emotions and thoughts associated with working in surgery. I suppose that it is possible that I will come to feel differently about a case like Mr. J's. But, at this point in my life, I simply feel that a respect for individualism and diversity, as well as the lack of utility, are reasons enough to refrain from making comments like those made while Mr. J. was sleeping.

I believe that the factors that often cause personal frustration are the ugly package in which understanding, or mere tolerance are wrapped. It was a memorable thing to watch the surgeon so easily pull the ribbon from Mrs. Reds's package that day. It taught me a lesson I will not soon forget.

Cancer and Hope

I began spending time with cancer patients on a somewhat regular basis in January of 1994. My nametag read "Volunteer," but I never did much for the hospital. I just walked from room to room talking with any patients that would listen or talk to me. I was surprised to discover that cancer patients are so willing to have lengthy conversations with a stranger. I recall the anxiety I had about saying the wrong thing or asking the wrong questions. I had visions of patients violently responding "How do you think I'm doing, I've got cancer!" to a simple "How are you today?" Not so. It turns out that I never once had a negative experience talking to these patients (maybe I just picked the right people to talk with). After a few weeks of spending time on the cancer floor, it seemed to me that terminal disease, if it is fair to label it as such, had a way of humbling a person and allowed them to speak freely and honestly. I began to learn a great deal about what people want, what they hope for, and what they fear when staring the entity of cancer in the face. I learned a lot about their needs, especially from a young man I will call "Al".

I had the pleasure of meeting Al not too long after I began spending time on the cancer floor. My encounter with him was a bit different from my usual encounters up to that point, given that we were both the same age, students, and academically oriented. I'm sure I appeared awkward as I talked to Al for the first time. I was still very green at that point. Al's calm and warm personality soon relieved the pressure I felt, and we began to talk openly. We talked about nurses, the accommodations of the hospital room, we even watched a portion of an old cartoon showing on the television. We spoke about school and about Al's plans to travel to Europe for a few months after his treatment was complete. I remember Al light-heartedly joking about his hair, or rather the lack of it. We continued with what I considered a very pleasant conversation that lasted quite a while longer than most I'd had to that point, and most I've had since. I left the room feeling, as

odd as it seems, uplifted. This young man seemed to be on the upswing - full of life and in good spirits despite his unfortunate situation. Indeed he was. From what I could tell, things looked good for Al.

I went back to the floor conference room to share my experience with a hospital social worker who, interestingly enough is the person I most enjoy discussing medicine with. This was a usual occurrence during my hospital visits. It was during this discussion that I learned the biology of Al's situation. In July of 1993, an egg-sized painless tumor appeared in Al's thigh. A soft tissue X-ray showed nothing of importance or alarm. It was decided that a waiting and watching period would be best, three months specifically. By October, it was supposed that the mass was a calcium deposit and not to be considered a threat. More waiting ensued. Eventually, the mass was removed in May. It was not calcium, but rather an unclassified sarcoma. Al was diagnosed with soft-tissue sarcoma and chemotherapy and radiation followed. Eventually, lung mets appeared and Al's situation appeared grave. It was at the tail end of Al's treatment for these problems that I met him. His hearty recovery was to the surprise of those treating Al, enough so that Al earned the title of "miracle boy" among the hospital employees. He left the hospital not long after I met with him, and he began his transition from patient back to person.

So what? What was done potentially wrong during Al's treatment process? An atypically young man develops a cancer, has what appears to be minimal chances of survival, amazingly overcomes his illness, and goes home. A story of hope, but is there an issue hidden here? Yes, and according to Al it lies in the concept of medical paternalism, preservation of hope, and sensitivity in a medical environment. What cannot be learned from looking at Al's charts or from reviewing Al's recent medical history are the conflicts Al had with his treatment team, conflicts of communication.

Some time passed, and I decided to talk with Al more thoroughly about the problems he had with his physicians. I wanted to understand his perspective. I called him

and asked him to meet me for lunch and talk with me about how things were going. One week later, I sat at a table with Al and adjusted to his appearance with a full head of hair. His personality mirrored that of the individual I met months earlier - still positive, still friendly, and very willing to talk. It was clearly evident to me that Al had done a fair amount of thinking about his treatment process, and he had some problems with it. I decided before I ever sat down with Al that a good starting point would be to have him describe to me the relationship he felt he had with his doctors. Al told me, among other things, that he felt his doctors were "too cold and matter-of-fact." He also expressed his void of any good feelings at all for one physician in particular. He then voluntarily made a transition into telling me about the manner in which he found out about his problems, the aspect of his treatment that is most upsetting to him:

"I am a very independent person.....It's just the way that I am and the way I've always been. But, my mother is more fragile," he told me.

He further described character traits to me that clearly gave evidence of Al as the stoic, and his mother as the epicurean.

"Since my mother is this way, I am very resentful that my parents were told of my illness before I was told. I should have known prior to them knowing. This is my biggest complaint," he said.

It was indeed the case that Al's parents were told of his illness and treatment plan before Al even knew of his problems. I do not know precisely how this came to be. It may be that Al's parents requested from the physician that they be told of their son's conditions before Al, and the physician respected this request. Maybe the physician intended to tell Al's parents and then immediately tell Al, but was kept from doing so. In any case, Al clearly expressed to me that he was upset by a feeling exclusion from personal matters.

"Were there any other incidents that disturbed you?" I asked, knowing from talking to hospital staff that Al had been clearly upset by some other incidences.

"The way I found out about the mets in my lungs was not right. I literally had to force my doctor to tell me over the phone. He wanted me to come in so he could tell me there [at the doctor's office], but I wanted to know then. I was at work and I couldn't just leave. It angered me having to force the doctor to tell me facts about my own body when I directly asked for them."

Al cynically laughed as he made this last statement - a symbol, I feel, of his disgust as well as his amazement that he was not able to freely communicate with his doctors any better than he did.

As our conversation continued, it seemed to me that throughout his time in the hospital, Al was not being told everything about his medical outlook. Al shared that in hindsight, he felt he was paternalistically handled. The doctors were simply not providing Al with enough information about his disease process to satisfy him. They were instead providing choppy information in a manner that Al considered cold and business like. This style of communication between a doctor and a patient, especially a younger patient like Al, is intended to preserve hope in the patient by providing only limited information. It is the idea of ignorant bliss, or "what you don't know cannot hurt you." Indeed, this is true in some cases for some patients, but in my opinion it is a somewhat arrogant approach on the part of the physician. The point in his treatment where the consistently paternalistic cover-up of the truth back-fired came with what I have referred to as the ear ache episode during our conversations. It took a good chunk out of Al's respect for medical personalities.

"I've been having some inner ear pain for a little while now, and I just wanted to get things checked out before I leave for Europe," Al said to the ER resident. Al was concerned that his long awaited and anticipated trip might be interfered with by a medical problem.

"You might have trouble during your flight if your ear is infected and bothering you," said the doctor. "And besides, according to your chart here and looking at your medical history, you do not need to leave the country for a few years."

Al was taken back; this was the first he had heard of such advice. He expected the worst to be a delay in his trip, not someone telling him he couldn't or shouldn't leave the country at all.

"Yeah, don't get your hopes up....sarcomas usually come back," said the Doctor.

"I could hardly walk by the time I got to the cancer floor," Al told me as he described his feelings immediately after being told this unexpected information. He explained how he could not believe that he had never been told this information before, not once throughout his treatment. Why had it taken a visit to an ER doctor, a total stranger to Al, to find this out? This was clearly upsetting to Al, as it would be to most anyone in the same situation. Not only was it upsetting to be told such information so late in his fight against this disease, but the manner in which the ER doctor stated the medical facts was clearly lacking in sensitivity. Ultimately, however, Al was able to take his trip to Europe, and his ear infection did not interfere at all. Al disregarded the ER doctor's advice.

Our conversation was coming to a close, so I asked Al to give me one directive that he felt, if followed, would have made his experience better. He simply told me that doctors should shoot straight with the patient, from the start. I agree to an extent. I know that if I had been Al, that is exactly what I would have wanted. And, I feel that with some conditions, (to be explained later), it may be the best approach for *most* people.

When I consider the information I know about Al and his story, it stirs emotions in me that support a feeling that Al might have been handled differently (implying better). But I have one side of the story, and this can be a dangerous thing. I have sometimes wondered if Al was told certain information and simply did not *hear* what he was told. Did the development of frustration in hindsight somehow enhance the anger he expressed

to me? Possibly, I have no way to know. However, if I assume that Al's personal story and its details are completely accurate, I am able to understand his feelings and agree with his complaints.

The issue raised in Al's story, that of the ethics of withholding information or lying to serve the patient, is one that arises with more frequency than I originally guessed. The scenario in which such paternalism appears spans a very wide spectrum. There are all types of illness and treatment plans about which information is withheld because it is thought that the patient cannot handle reality. It is even the case that some physicians will withhold information from patients not because of a motive to preserve hope, but rather out of pure personal discomfort - the difficulty of looking the patient in the eye and speaking of death. In instances like this, it is rather obvious that the patient stands to suffer unduly because of the physician's unwillingness to speak of a very difficult topic. I will, therefore, disregard such practices as these seem clearly unethical, and I will instead continue to focus on nondisclosure motivated by paternalism. The following case is one of another cancer victim, and it stirred emotions in me that were very similar to those I experienced when I spoke with and considered Al:

Mrs. Anna Domingues, a fifty-four-year-old woman, was born in Puerto Rico but lived most of her adult life in New York City. She came to the hospital with a complaint of severe abdominal pain and went to surgery on a Wednesday morning.

The medical student assigned to her case was unsure about what she should be told. He spoke to the resident responsible for the patient, telling him that Mrs. Domingues had stage-four cancer of the cervix, the most advanced stage. They had cleaned out all of the tumor they could see, but since it had spread to the pelvic wall, all they now could do was try chemotherapy and radiation. The five-year survival rate of stage-four cancer is 0-20 percent -- bleak news for the woman.

The medical student was tempted to keep the information to himself, at least for the time being. He thought it could produce a severe depression, and maybe Mrs. Domingues would not cooperate as well in chemotherapy and radiation. On the other hand, he felt that it would not be fair to her to withhold the potent prognosis: somehow, she had a right to know her fate.

The student discussed the problem in turn with the resident, the attending physician, the staff psychiatrist, the hospital chaplain, and a social worker. An enormous dispute emerged. The attending physician was adamant that such bad news should not be disclosed, at least not with the full force of its meaning. The hospital chaplain was equally adamant in the other direction. The social worker seemed to side with the chaplain, stressing the need to prepare for the care Mrs. Domingues's three adolescent children were going to need. The resident was confused himself but reflected the consensus of the majority of his profession; he reluctantly concluded that it would be inhumane to let the woman know her poor prognosis. (4)

The frightful questions I initially experienced with the issue in Al's case and the case above were exactly the same: Is it fair for the provider to make judgments about what level of information the patients wants and can handle, and what happens when this judgment is incorrectly made? Is it acceptable to withhold information from a patient who wants it? Furthermore, do physicians risk revealing information to a fragile patient only to have that patient plummet into despair and lose the willingness to fight disease or cooperate with treatment? Trying to answer these questions was hard for me. I certainly feel, and am willing to state it as fact, that every individual handles bad news in a different manner. Some deny, some build barriers, some give up, and still others fight harder. Once, I even read of a man who claimed that discovering he was HIV+ enhanced his life by forcing him to slow down and enjoy what were previously insignificant aspects of life. With this type of variability in coping methods, what is right for the physician to do and say? Mandating that every patient always be told every aspect of his or her disease does

an injustice to those who are harmed by knowing, while setting a standard of consistently withholding information is a definite downfall for all of the AI's out there.

In my view, the situation is quartered into four distinct possibilities as follows: 1) The patient requests disclosure of all information, is granted this disclosure, and is satisfied that their wishes were granted. 2) The patient requests nondisclosure of medical information, is kept uninformed, and is therefore appeased. 3) The patient desires disclosure, but is paternalistically denied complete information. 4) The patient is made aware of all medical discoveries, regardless of his or her wishes to remain uninformed. Each of the four circumstances carries with it some consequences. It is easy to see that 1 and 2 are acceptable scenarios, given that the patient is truly pleased and the physician is willing to play the pertinent role. Scenario 3 however, potentially insults the patients autonomy. It disregards the individuals self-determination, and will often times leave the patient disgruntled. However, scenario 3 spares the patient of potentially damaging news and can allow for more effective, expedient recovery as a result of a maintained level of hope (or at least this is the intention). Scenario 4, when compared to 3, is the flip side of the coin. The patient is made aware of all information out of respect for the patient's right to know, but the potential for destroying hope is in full existence.

It was easy for me to conclude that the best way to approach the issue of truth telling would be to produce physicians who could somehow know with 100% assuredness how a patient will react to given news, but there is no such thing as a soothsayer; physicians simply have no way to know exactly how a patient will react to medical news. They can only predict according to the clues gathered from what they know of the patient. Given AI's independent and head-on approach to life, it is my belief that he probably would not have plummeted into despair, never to recover, had he been told everything about his treatment and disease. He certainly would not have ended his trip to the ER at the cancer floor nurses' station in tears. Likewise, Mrs. Domingues might have been fine having the knowledge of her cervical cancer revealed to her. In fact, she may have been grateful to

know of her medical situation so that , although she faced a statistically likely death, she would then have the time and awareness to make preparations for her death (i.e religious preparations, familial amends, etc.). It is possible that both Al and Mrs. Domingues could have maintained hope for recovery and perhaps a hearty will to fight, even if each had known all of the facts. There is no way to know for sure. Al has told me in person that he believes his attitude and will to recover would not have been damaged.

It would be foolish for me to talk myself into believing that every individual has the ability to accept and fight disease. I have already stated my belief that no two people handle such things in the same manner. Certainly there are a great number of people who in Al's or Mrs. Domingues's situation would throw in the towel and give up immediately if they knew everything their own bodies were doing to them. In thinking about people like this, I recall a story once told to me in detail by a hospital nurse. It was about a woman I call Betty: For five years, Betty had been noticing a lump in her breast, but the fear of what it might be kept her from visiting a doctor. The lump began to grow, to the point that superficial tissue necrosis began. Betty had to go to the doctor at this point. After an exam and tests, the physician revealed to Betty's family only that she had highly advanced stage cancer, and the prognosis was a maximum of three months. The family opted to not tell this information to Betty, and they requested that the doctor do the same. As a result, Betty was kept in the dark. It has now been four years since Betty's original prognosis of only three months, and she is a cancer survivor. She has now been told of her original prognosis and she stoutly believes that had she been told originally of her situation, she would have gone home, given up, and died within the allotted three months - a self-fulfilling prophecy. She claims that all hope would have been lost. It seems as though withholding information from this patient was right; it seems to have had the intended and beneficial effect - preserving hope. But, what does the word "hope" entail? Certainly the word hope denotes a concept that has a great deal of flux in its definition. Disease has a way of causing shifts in hope. Dr. Howard Brody writes:

"If we were as good at listening to our patients as we are at telling them things, we would learn that hope is not automatically equated with survival. Hope means different things to different people; and hope means different things to the same person as he moves through different stages of his illness and his emotional reaction to it. The man who last year hoped for a cure for his arthritis may now hope that, on a good day, he can get in nine holes of golf." (5)

I could not agree more with Dr. Brody. Hope does indeed seem to be a chameleon that adjusts its color to suit the surroundings. I recall an experience that broadened my definition of hope. I once talked with a patient who was a trauma victim. That day he had managed to walk 50 paces before stopping to rest. He told me with delight that he knew he could go 60 paces tomorrow. This man hoped for nothing more on a day to day basis than a few more steps. He told me that this progress carried him through each night. Given all of my experiences to date, including the people I have met and what I have read, I have come to the conclusion that it is not acceptable to withhold information from a patient because it is thought that hope will be lost. It is reasonable to think that hope will change, and indeed be lost in some cases, but there is simply no easy way to foretell what will happen. Betty herself may not have reacted as badly as she thinks had she been told of her cancer and its severity four years ago. I believe the right of the patient to know and the principle of autonomy are to be respected prior to a reverence for hope, which I have already shown to be a fluid concept. Hope is too powerful to fall by the wayside however. In combination with a respect for autonomy, there should be a scrutinizing attempt by the physician to present tragic news so that the subtle, if not drastic, changes in what is reasonable to hope for are brought immediately to light. These are the conditions to which I made reference earlier, and it is in this manner that I feel both Al and Mrs. Domingues should have been handled. It is interesting to note the following

statistic regarding disclosure to cancer patients, " In 1961, eighty-eight percent of the physicians surveyed indicated that they sought to avoid disclosing a diagnosis of cancer to the patient, but by 1979, ninety-eight percent of those surveyed reported a policy of telling the patient." (6) So, it is clear that a shift has been occurring in support of disclosure. This is a shift that pleases me, after listening to Al's story.

It would be an incredible blessing and talent to be able to predict exactly what is best for each patient, but I will never be able to predict the future for other people. I do not yet know the full scope of considerations when contemplating disclosure vs. nondisclosure to a patient, but my personal reverence for truth and an eye-to-eye approach to personal problems makes me think that disclosure is best. I understand that the physician is often placed in a dilemma, cornered by personal anxieties associated with telling patients bad news, an awareness of patient autonomy, and a desire to avoid the impairment associated with destroying hope. I understand that nondisclosure may have, and indeed has had benefits when treating certain patients. Yet, for whatever reason, when I reflect on this issue, it often comes down to asking myself the following question: If it were required to from a policy that mandated consistency of disclosure or nondisclosure, which would I choose? I always end up leaning towards disclosure. In Al's case, I feel it would have been best had Al communicated to his physician the desire to know of any conditions prior to his parents. Likewise, the physician would have best served Al by adhering to his patient's requests and communicating frequently with Al about hope and his disease. It has been my experience in life that talking out the unknowns can do just as much for preserving and promoting hope as remaining in a state of ignorant bliss.

"Cindy Will Give You What You Want"

What does it mean to say that a physician is "treating" a patient, or that the patient is "under a doctor's care"? Certainly a large number of activities are included, but often times to be treated or under the care of a physician simply means to be actively taking prescription drugs. Drugs are miracle workers and are the tools that hang from the work belt of the physician. It is truly amazing to me that the sciences of chemistry, biochemistry, and physiology have given rise to such an army of chemotherapeutic agents - little capsules or disks of chemicals that magically ease pain or heal the body. Unfortunately, drugs may be easily abused, like many of man's wonderful advancements. This is a fact almost everyone is aware of, even small children. Entire cities around the globe, like Cali, Columbia, make their mark in national news due to the prevalence and industry of drug abuse. But what of the subtle drug abuse that occurs among the most unlikely sect of our society - physicians? I am not referring to personal abuse and use on the part of the physician (which is not uncommon), but rather the drug abuse that is the result of a physician's actions and has its effects on the patients. It seems that such abuse can take two forms: the physician can refuse to prescribe or administer a drug, motivated by a fear of patient dependency, a rather alternative approach to the concept of drug abuse. Or, the physician overprescribes a drug for a problem that may require therapy outside the realm of chemicals. I will give personal experiences that are examples of each type of clinical drug abuse:

There is a definite negative connotation to the words addiction and dependency when used in a medical environment. This is a just concern as chemical dependency often leads to further problems and may even be morally objected to by the patient. However, sometimes addiction is not the boogy-man so often feared throughout narcotic and opioid drug administration. Sometimes addiction is an almost required side-effect for palliative

care, especially for a terminal disease process. Yet, "if a patient who has experienced pain relief with opioids demands them, even for cancer pain, that patient can expect health care professionals to accuse him or her, either overtly or by innuendo, of being a drug abuser."

(7) This is a title that may bring undue guilt to the patient. I spoke with a medical technologist once, and he shared a story that illustrates the fear of dependency depicted by this quote. He remembered and told of a particular physician who considered drug dependency an evil across the board. There seemed to be complete consistency in his evaluation of dependency as something to be avoided. This doctor was treating (or in this case, not treating) a bone cancer patient with extra strength tylenol with codeine for pain control. Perhaps this is the only pain prevention the patient needed, but this is highly unlikely given that bone cancer is a very painful condition. Safely assuming then that the patient was in need of a significantly stronger pain killer, was the physician doing an injustice to this patient by refusing to listen to or respond to the signs for necessary increases in drug strength, even though his motive to avoid the negatives of drug dependency was genuine? When considering what I know of this case - yes, without a doubt. I wonder, what is so wrong with drug dependency in such a case? I don't know if there is something harmful about drug dependency that must be guarded against for medical reasons; I'm sure it would vary from drug to drug. I do feel certain, however, that there is nothing morally objectionable about dependency throughout the last stages of life. The severely depressed patient is for a time dependent on Depakote to avoid the unpleasantness of depression. Why then should a bone cancer patient be denied freedom from, or at least reduction in, the extreme pain of such a condition? I see no viable reason, especially if the patient is facing an almost zero chance for survival. I think the protocol for advanced stage cancer patients should be one of highly stressed palliative care, even if this means drug dependency for the patient. For those who disagree, I would recommend paying attention to the distress and pain of a patient on a cancer floor, and put yourself in their position. Then, compare it to the "evil" of dependency.

While I believe dependency to be an acceptable outcome of efforts to control the pain of a terminal cancer patient, I certainly see instances where dependency develops and it should not exist at all. Prescribing opioids at addictive levels and frequencies is not at all comparable to such prescriptive tendencies when treating, say, a patient with occasional recurrent headaches. I spoke with a rural care nurse practitioner whose story made it obvious to me that physicians sometimes wrongly use their prescriptive authority to save their own time, easily treat patients, and avoid real problems - all at the cost of producing an unnecessary drug addiction. As the following account is read, it is important to know that this is the story of one particular physician's style of practice. It is not meant to be a condemnation of drug prescription as a whole (certainly that would be foolish).

Cindy, the nurse practitioner, worked for a family care doctor in a small southern town. Her approximate year long stay as this doctor's nurse practitioner came to an end in part due to the practices of this particular physician, as well as other personal reasons. It seemed, according to Cindy, that the doctor had created unnecessary drug dependencies within his patients. She specifically described a particular patient, an obese man with low back pain. In Cindy's professional opinion, the pain was most likely due to a sedentary lifestyle in combination with excessive weight and poor posture. Yet, the doctor had prescribed narcotics for the pain, and ended his treatment with this action. It became commonplace for this patient to appear at regular intervals to get his drugs, a prescription he no longer needed for therapeutic reasons, but rather for physiological addiction reasons. Cindy would become upset when the doctor would shunt what she saw as questionable prescriptive tendencies to her. "Cindy will give you what you want," she recalled the doctor saying in this case and the others like it. Eventually, Cindy became frustrated by this approach to medicine. She became disenchanted with the process of giving high dose prescriptions to obvious hypochondriacs or depressed patients who were struggling with dysfunctional families. The medical creed of "do no harm" seemed to be falling by the wayside, and Cindy did not like it. It was too much; this doctor had a whole

collection of patients who were dependent on their prescription medications. Cindy even told me of a patient who had been caught adding "0" to her prescription amount, and yet the doctor continued to regularly give this patient the same prescription. This was Cindy's initial work experience as a new graduate from graduate nursing school, and there was a teeter-totter in her thoughts during the time when she was witnessing this style of subtle drug abuse. What should she do as the doctor's primary assistant? Well, eventually Cindy decided to leave the practice, in part due to these types of witnessed problems. Kudos to Cindy.

What is at the root of the problem observed by Cindy? Why would a physician, a family practice doctor, hurt his patients by prescribing addictive drugs for invalid reasons? The problem seems to lie in effective communication and acceptance of the role as counsellor when becoming a physician. The patient with the low back pain had an obvious problem that seems to have required action beyond treating the resultant pain. Perhaps the patient had a hormone imbalance, perhaps he was simply an inactive over-eater, or perhaps he was a food addict (in which case, he is now a food addict and drug dependent!). Did the doctor disregard the necessary treatment for these possible problems simply because it is obviously easier and quicker to jot down a few notes on a prescription pad than it is to face the problems with the patient? If so, this physician is sloughing off his duties as a doctor and is doing the field of medicine harm. I understand that the patient may have been experiencing enough back pain to warrant the use of narcotics, but these only temporarily relieve the pain and therefore should be given in combination with therapy to solve the problem. The cases of the hypochondriac and depression patient demand even greater attention by the doctor and even more communication due to the nature of these problems. Masking a problem behind the stupor of high dose narcotics does not seem to be the answer. Putting energy into the necessary communication and possible referral therapy is the answer. It is certainly scary to think that as a patient,

simply following the doctors orders could lead to an unnecessary drug dependency. It is even more scary to think that the drugs might not have ever been needed in the first place.

To Cindy's knowledge, this physician still practices in a similar manner. Is he doing something morally wrong? If I consider the possibility of a more viable treatment that may include only temporary narcotic use, I think I must answer yes. It is certainly possible that this physician tried everything within reason before resulting to such therapy - I only have Cindy's account of the practices at that clinic. If the physician has exhausted all other possibilities, perhaps such drug dependency is the only thing that can be done. I get the feeling from Cindy, however, that this was not the case.

In summary, I suppose that I feel drug dependency to be acceptable in terminal patient situations. Conversely, I do not see it as acceptable to resort to chronic narcotic use for depression or obesity.

Perhaps A Loss of Faith

What is one of the primary reasons physicians are sued for malpractice?

According to a 1995 study done by Vanderbilt University researchers, the physicians most likely to be sued are those who, basically, have poor bedside manner. After surveying 963 female ob/gyn patients, "the doctors who were sued the most elicited twice as many complaints from the women as those who had never been sued. Invariably, the women felt that they were rushed or ignored on their visits, or that their questions were not answered." (8) It has been my experience that what patients want is time, and a thorough understanding of their situation. They want to feel as though the doctor is there to answer any questions, rather than answer only the questions he or she has time to deal with at that moment. And, the doctors do not want to be sued. It seems like a rather easy formula - the doctor provides his or her services and answers all of the patients questions, and in turn, the patient is satisfied - resulting in fewer legal battles. But, there are two main problems in my view: First, doctors are indeed rushed at times, and the clock becomes the enemy. Second, some patients are going to sue regardless, motivated by the anger that stems from medicine's failure to help them, or out of pure and simple greed. So, I began to wonder - where is the middle ground; what is reasonable to expect from a visit to the doctors office? I had the opportunity to investigate with one particular patient what she considered a partially faulty physician-patient relationship. The expectations she had of her physician seemed quite reasonable:

Connie had already had a brain tumor removed and was facing cervical neck surgery the first time I spoke with her about her relationship with the surgeon she had come to know as a result of her medical needs. This particular surgeon is held in high regard in the area as one of the very best - a good technician with incredible surgical skills. Connie was quick to agree that she had made the right decision when I implied that,

strictly considering ability as a surgeon, she had picked the star player. But when Connie and I began to converse about her relationship with this doctor, her comments were less of praise and more of disappointment. According to Connie, this surgeon is simply void of a personality and does not know how to "just talk." She described the scenario of one of her office visits: The doctor staring at the examining room floor, robotically making statements of medical fact, and eventually leaving with the same unapproachable aura. She even described the way the surgeon once spoke directly to her husband, and not once looked at her - the patient - as he described her medical conditions. Connie felt that no effort was being made to communicate with her, or even worse, the ability to communicate might not even exist. It just so happened that I knew this particular surgeon, and I had the opinion that he did indeed have the ability to communicate with his patients, but he chose not to do so. It became obvious that Connie did not like the fact that her surgeon fell in the category of what might be called a cold, had-nosed professional, but she was clearly not exceedingly upset by this. I asked her if she would go to him if she had it to do over again. She said yes. I asked if she felt she might be more likely to sue this surgeon than another, given his personality and disregard for establishing a good relationship. She said no. Connie then elaborated on why she went to this surgeon, and what she wanted from him. She chose him for his reputation as a surgeon, and went to him for no other reason than to maximize her chances of successfully going through neurosurgery. This stance seemed logically sound and sensible to me. She chose the best mechanic out of the list from which she was able to choose. There was no intention of a lasting relationship, just the need of a surgeon's skills. Yes, it was disappointing that the doctor couldn't or wouldn't communicate with her any better than he did, but Connie saw this as no reason to be more apt to sue him if something went wrong or was mistakenly done incorrectly. As Connie put it, "His job is to be extremely focused on what is right here (she clutched her hands at arms length).....and he is good at it!"

Connie's position is a viable approach to selecting a physician, especially a surgeon. Or, rather, it is a viable approach for her. From my exposure to ill people, it seems to me that some, if not a large number, of people must have the reassurance and extra time of a physician; they must have a reasonable expression of compassion. When the young pregnant mother-to-be seeks out an obstetrician, she is not necessarily more concerned with the doctor's ability to work with "what is right here" as she is with the doctor's willingness to let to rest any unnecessary anxieties and answer the mirage of questions that come with pregnancy. Likewise, the recurrent family practice patient wants to feel as if the doctor knows him or her, and has put thought into the medical situation beyond biology.

While the nature of the patient physician relationship is not as morally intense an issue as abortion or euthanasia, it is an important issue nonetheless. This relationship seems to be a facet of medicine that is very intricate and has its roots at the very heart of what it means to be a good physician. There is not a right or wrong per se with the dynamics of a patient-physician relationship, but rather a collection of responsibilities that if the doctor is polite and the patient aware, should be followed. The physician should try to provide for the needs of the patient, even if this means spending a bit more time to answer all of the patient's questions. It is nice when the physician doesn't let the clock push him or her out of the room too soon. Meanwhile, the patient should try to remember the ultimate intent of the doctor and realize the sometimes extreme time demands of medicine. If the patient is dissatisfied, they always have the right to speak their mind, and they sometimes have the right to change doctors.

There is no law that says "You as a physician must make good eye contact and talk to your patients in a compassionate and concerned manner," perhaps there should be a law like this. However, there will most likely never be such a decree. So, after much personal reflection, the situation seems to boil down to the following for me: Patients must hope for an approachable, freely communicating doctor, and the doctor is responsible for

providing the patient with proper care, according to what the patient wants from a conversation from the doctor. The physician who either forgets or chooses not to bear the responsibility of assuring quality communication with his or her patients, in my opinion, disregarding one of the most important aspects of medical treatment. But, at the same time it is sometimes hard for me to grasp exactly what is *morally* objectionable when a physician does his or her best with the time the clock allows. There is no doubt, however, that it is best when a doctor will listen to whatever the patient is willing to lay on the table (pardon the pun).

Connie's case is one wherein a decision to maximize her chances in surgery came at the cost of a personable relationship with the doctor. Connie made a personal value judgment, and acted accordingly, realizing that she had made a sacrifice. But what happens when a patient like Connie unexpectedly dies, and the family is not so understanding? What happens when the family cannot help but to lash out at someone for their loss, this someone being the doctor, regardless of his personality? This is the type of situation that leads to a court summons. Indeed, such litigations are valid in some instances. For example, the physician who wantonly harms or takes the life of a patient should certainly fall under the gavel of our judicial system. Likewise, the doctor who repeatedly exhibits results that are indicative of substandard practice or unsuitable knowledge must also be subject to court action. I am not referring to these and similar case types, but I am rather referring to cases where the patient dies because the doctor makes a mistake, "an error in opinion, understanding, perception, interpretation, or judgment," as Webster puts it. Is there a safeguard against doctors being sued for a single mistake? I have wondered for some time about this, in part due to a personal fear that I am not sure is warranted. I have pondered what it will take for people to realize that medicine is not exact, that things go wrong, and most importantly - the unexpected happens and mistakes are made, both of which demand acceptance. As far as I can see, there is only one conclusion: Humanity must give up a bit of its faith in medicine (that's

right...it might be possible that we have too much faith in something). The physician who claims he can save anyone, and the patient who believes this, have a blind faith in a science and art that still seems far too uncertain to warrant such claims.

I very recently had a one page magazine article given to me by a close friend, the topic of which was the suing of doctors when the expected result of treatment does not come to pass. A man named Alan Blodget recounts in the article his rather quick metamorphosis from a vengeance-seeking son of a prematurely deceased father to a more understanding, and in my opinion, reasonable man. He recounts the logic behind his ultimate decision to not sue the surgeons who accidentally and indirectly killed his father via unexpected drug reactions during their efforts to treat him:

"It was simply my realization that we expect too much from each other. We refuse to accept that we make mistakes, that even the best of us screw up.....I know that forgetting the lettuce in a Big Mac doesn't compare to making an error that costs a life. The stakes are higher in an operating room. Nor am I opposed to lawsuits that seek to punish those who hack off the wrong leg or knowingly sell products laced with danger. But to sue someone for failing to be the god we wanted strikes me as wrong." (9)

My knee-jerk response is that Mr. Blodget has a good approach to his unfortunate situation. It is pleasing to see that he realized it was just that, an unfortunate situation. I do not believe that the invalid suing of physicians is an out-of-control problem in this country. Every physician I have talked to about this topic seems to agree. In fact, I once asked a dermatologist if he'd ever been sued. He replied, "It's interesting that you should ask me that question, because I am going through my first lawsuit right now. Yep!....a guy who's not even a patient of mine tripped on my office sidewalk step, and he's suing me!" He laughed and so did I. But, I realized talking to him as well as the other physicians I spoke with, that although being illegitimately sued as a physician may not be one of the poster children for medical ethics, it does involve enough energy and time to be

frustrating and a hindrance to provision of care. When I envision myself as a physician being sued, my biggest frustration is simply that so many litigations seem unnecessary.

Perhaps if individuals would not expect godly miracles from the institution of medicine, and not sue when things uncontrollably go wrong, the doctor would have a bit more time to talk.....a bit more time to explain their efforts, rather than defend their reputations.

The Virtue of Patience

"In general, proxy consent on behalf of a formerly competent person with previously expressed wishes requires that such consent accord with those wishes.....in such a case, all concerned may rest easy in the knowledge that they are merely carrying out the stated wishes of the patient and therefore, face no moral dilemma." (10) This seems rather straight forward and viable, or at least it did until I learned of and reflected upon Ellen's story.

Ellen is a middle-aged woman with a husband and one child, a daughter. Some time ago, Ellen was being treated at hospital A on a regular basis. She was receiving treatment for leukemia. Ellen, acting in what I consider a responsible manner to which others should pay attention, had an advance directive, a living will. She accepted that her life was in danger, and she made the pertinent decisions. In a stable and lucid state, Ellen put to paper her decisions regarding her own treatment and mortality. On her living will, there was a segment that addressed the possibility of tubal feeding, and it appeared as the following:

ARTIFICIALLY PROVIDED NOURISHMENT AND FLUIDS: By checking the appropriate line below, I specifically:

☒ **X** authorize withholding and/or withdrawal of artificially provided food, water, or other nourishment or fluids.

☐ **DO NOT** authorize the withholding and/or withdrawal of artificially provided food, water, or other nourishment or fluids.

(11)

Ellen did not want to be hooked up to a tube. The thought of a vegetative, sedentary lifestyle was obviously unappealing. She made a hypothetical quality of life

judgement that is demanded by the thoughts that are spawned when considering the living will. With this will accounted for, Ellen continued to receive chemotherapy at Hospital A, but it was eventually decided that Ellen might be better off at Hospital B in another part of the country. So, Ellen and her family travelled to hospital B. Although Ellen was not as pleased with the environment she experienced at hospital B, her treatment seemed to be of some success, and a rather confident Ellen told her family to go on home. All seemed fine, and Hospital B would fly her back to Hospital A soon.

It was after Ellen's husband and daughter left Hospital B that things took an unfortunate turn for Ellen. She began to experience severe nausea and unexpectedly suffered a brain aneurism. This occurred at a time when her platelet levels were still considerably low due to her leukemia therapy. Surgery ensued, and in the end, Ellen was left with only minimal brain activity, a tracheotomy, and constant IV feeding. Hospital B suggested that Ellen be sent home to "expire" in a familiar place and with her family. About two weeks later, Ellen was indeed sent back to Hospital A, with the feeding tube still in use. So, Hospital A is placed in the following situation: Ellen leaves with the intention of being treated at Hospital B only for her leukemia. However, she returns having been effectively treated for her cancer, having been through trauma surgery, hooked up to a feeding tube, and nonresponsive. Hospital A still has in front of them the living will with what is now a very confusing "X" beside a request to withhold or withdraw tubal feeding.

Now comes the question raised by Ellen's case: Is treatment and tubal feeding continued against the clear expressions of disapproval the once competent patient made, or is this advance directive overridden out of a familial decision that there is actually a hope and desire for continued treatment? I remember thinking, what an incredibly hard question for anyone other than the patient to answer! But, in cases like this, someone has to make this decision, and according to the President's commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, "the decisions of

the patient's families should determine what sort of medical care unconscious [incompetent] patients receive." (12) Thus, the family is faced with the difficult task of deciding if the prior autonomy of a loved one should be adhered to, or if treatment should be continued. I have tried intensely to put myself in the shoes of Ellen's family and others in similar situations. I have tried to imagine that someone dear to me, say a wife, is in the hospital bed while a sheet of paper and a decision lies in my hands. The emotional struggle seems overwhelming. Respecting the written wishes of my wife means doing something that leads to the death of one of the most important people in my life. Yet, overriding the advance directives means leaving my wife in a physical state that she herself deemed unsuitable for continued existence. When I have thoughts like this, I usually indulge in a luxury that Ellen's family did not have - I usually ease my mind by thinking, "I just don't know what I would do....thank God I am not in that situation." But, this does nothing for solving the issue involved. Ellen's family had to do something for the wife and mother of the family, even if that something was leaving Ellen as she was.

It was during the time when Ellen lay nonresponsive in a room in Hospital A that I met her. At this same time, decisions were being made on just how her treatment should be continued. Prior to going in to see Ellen, I spoke with a hospital worker about my uncertainties regarding such situations. I also released the anxieties I had about speaking to a nonresponsive patient. I had never done this, and I was not sure if I would be heard or say the right things to Ellen. I talked to the worker about my thoughts and opinions on Ellen's case, and she emotionally expressed to me her thoughts, during which she said, "There's something in there behind those eyes; Ellen's in there." She believed Ellen was aware at some level and was treatable. We talked further, then I decided to go and talk with Ellen, to meet her.

I walked down the hallway and stood outside Ellen's door for a brief moment, then I entered. There she was with her machines and tubes all connected, seeming peaceful and content. I said the same thing I usually say when I entered a new room to talk to a new

patient, the same thing I'd said to Al, "Hello Ellen, My name is Derek. I am a volunteer here at the hospital. I usually just wander around and talk to patients who want to talk." The expected lack of response was a bit more awkward for me than I had hoped. I continued, "Looks like you are being taken good care of here," wondering if she was internally cursing me or agreeing with me. "It's a very pleasant day outside today," I said. Then, I cursed *myself* for letting the awkwardness of the moment push me into talking about the weather. As I continued talking about anything that came to my mind, I would occasionally take a pause and sit with Ellen in silence. I wondered if she was thinking to herself, "Please pull out all of these tubes, I don't want to be this way!" Or, perhaps she was intensely frustrated and scared that she had no way to communicate to others that she now felt differently than what is depicted on her living will. Maybe she was not thinking or hearing at all - purely at the mercy of others. This was my suspicion. Thoughts like this continued for a little while, then I said goodbye to Ellen, wishing her good luck as I left the room.

In the elevator lobby, I sat and thought about the situation. Again, I envisioned myself trying to decide Ellen's treatment path. I tried to make some comparisons. I tried to imagine a spectrum of situations where treatment is decided upon by people other than the patient. What about the motorcycle victim in the ER who begs to be put out or killed because he has lost both legs? Treat him, I decided with great confidence. And what about the drug abuser who is screaming frantically about her ability to fly and her right to choose to attempt doing so? Restrain her and treat her, I decided (with more confidence than my decision to treat the motorcycle accident victim). What of the six year old who fell from a tree and now lie silently in a coma, never having been able to even spell "advance directive"? Treat to the fullest, I thought.

Now, what about Ellen? I still did not know. Why was it so much harder to decide what should be done for Ellen than in the imaginary cases I had just envisioned? Why so much more deliberation? It did not take me long to realize the mistake I had

made in attempting to settle Ellen's case by comparing it to a drug abuser or a child. Treating these people did not involve disregarding a prior statement by the patient (assuming that no living will existed with a child or drug abuser). The imaginary cases did not involve overriding a written statement formed some time before the accidents occurred. But, in Ellen's case autonomy was a much larger issue. Ellen had requested to never be put in the exact situation she now was facing. This alone made it seem wrong to me to continue treating her. In a sense, I felt it was comparable to treating a patient who was lucid, pain free, and adamantly refusing medical help. However, I do believe that transformations from a hypothetical to reality can cause great shifts in personal desires and attitudes. What was once thought to be desirable to a person can take a 180 degree turn when the suspected scenario comes into full existence. In fact, I have thought of one personal experience that may be comparable to Ellen's situation in this regard. I remember thinking as a senior in high school that I would never go to UT - I would simply hate it there. Even after receiving the pleasant surprise of a scholarship and making a financial decision to attend UT, I felt as though I was going to the wrong place. Then, a strange thing happened. I came to UT, and loved it. After four years, I honestly believe that I could not have had a significantly better college experience anywhere else. What I thought I would never enjoy or do, became one of the best things I have *ever* done. Could it be possible that what Ellen once felt might now seem different to her? And, if not right now, what about five years from now? Perhaps Ellen would look back and realize that the best thing ever done for her was the disregarding of her living will. It is an approach like this that continued to do battle in my mind with the principle of autonomy.

Time passed, and Ellen's condition remained stable and unchanging. Her family ultimately decided to hang on to Ellen and keep her nourished tubally, hoping for some type of worthy recovery. As more time passed, Ellen began to make the hoped for progress that, according to the nurses, was very unexpected. Within a relatively short time, Ellen was able to talk again, participate in physical therapy, walk with the aid of

parallel bars, and ultimately go home with the family responsible for her opportunity to recover. I have not had the chance to see Ellen and talk with her since. Ellen and her family understandably wanted to share their time together free from anyone associated with medicine that was not specifically needed. I do know, however, that although Ellen does not recall anything about her ordeal, she is certainly not upset that she was treated and is alive. I wish I could speak with her today. I wonder what types of thoughts Ellen has about advance directives. But, Ellen's case says a lot to me, even without speaking again to Ellen herself. It completely exemplifies the fact that thoughts sometimes change when expectations actualize. It shows that sometimes there is indeed virtue in disregarding the advance directives of others. Ellen's story has forced me to be leery of a possible policy that would require strict adherence to the desires expressed in an advance directive. If such a policy existed at the time of Ellen's ordeal, she would not be here today.

After reflecting on my experience with Ellen, my thoughts are the following: There are often times several individuals involved in decisions about life and death in a hospital setting - the family, the patient, the physicians, even friends and estranged relatives in some cases. The roles each of these personalities plays in the process vary greatly from case to case as a result of differences among both the strengths of the relationships and moral standpoints. Living wills are intended to act as the patient's official statement to everyone of what he or she wants in given situations. These are good in that they lay the foundation for decision making and provide a starting point for each proxy involved. But, Ellen has proven to me that these documents should not always be followed precisely. Patients end up in unfortunate situations, situations just like those intended to be avoided when the living will is drawn up. But, a strict adherence to the wishes expressed in the living will leaves no room for a change of mind, even if this change of mind might not be realized for years to come. I think it is a reasonable approach to make all valid attempts to save the life of a nonresponsive patient, in line with

what medicine predicts is potentially helpful. Ultimately, however, the wishes stated in the living will should be adhered to if survival or recovery becomes unprecedented. For instance, I feel it would have been acceptable to withdraw tubal feeding from Ellen if after two years, she showed no signs of recovery at all. This way, Ellen is given the chance to recover (which in fact she did), but will ultimately have her wishes respected if recovery never comes. I suppose I support a "Grace Period for Living Wills" policy, especially when the living will denotes a subtle concept of euthanasia, as with Ellen's case. The autonomy of an individual should be respected, since value judgements about the quality of life are countless and very personal. Yet, I feel that the grace period approach is the key that unlocks doors of opportunity for the patient who might regret the decisions of yesterday, the decisions put on the living will. After the grace period, if the patient is still nonresponsive and not recovering, the directives of the living will resume their role as the key entity to be respected. I suppose that Ellen has made me think about the dangers of hasty decision making. It has been a hard thing for me to mesh this concept of grace periods with my personal reverence for autonomy, but I simply see no other way to maximize the chances for the patient and still respect personal wishes.

I have been forced to become aware that reading a sheet of paper stating "Do X, and Do Y" does not necessarily mean to do these things the first chance that becomes available. In fact, it may be a very dangerous thing to *not* deliberate. Yet, the patient's autonomy makes it a dangerous thing to wait too long. So, how long should the deliberation, the grace period, be? I do not know - perhaps this is something that every person should decide for themselves when filling out a living will.

"....She Works in the Bookstore"

The first experience I ever had with hospital medicine was as an emergency room volunteer. I thought this would be the way to really expose myself to the intensity of medicine. Indeed it was - I saw and experienced some very interesting things during my time in the ER. This was at a time when my desire to pursue the title of physician was still formative. I was not yet sure if I wanted to commit to a life of medicine. But, the experiences I had in the ER excited me and bolstered my enthusiasm for medicine. As a whole, I found very interesting the things I saw people doing and the interactions between people. I did, however, have a few experiences that disturbed me to an extent.

"Now just try and lie still, ma'am," said the hearty and well mannered physician to a nervous patient.

"Will it hurt much?" asked the middle-aged lady lying on the paper covered table.

"Just a little bee sting for a few seconds - we're just going to draw some blood from you," said the physician as he shifted his eyes to the lab technician, the sign to go ahead and start.

"Oh...I've had that done a few times before," the patient replied as she relaxed.

The physician disappeared behind a cloud of white curtains, and I watched as the blood was drawn. A few minutes later, the tubes of blood sat on the ER desk, as the technician scurried about collecting more of the same.

"Hey, Have you ever run anything down to the lab before," a clerical worker asked me.

"I am not sure if I even know where the lab is at yet....I've only been here for about a week now, every other day," I said. During this week, I had gone nowhere in the hospital except through two sliding glass doors and into the ER.

"Well, It's time you learned. From time to time, we will be asking you to take a specimen or blood sample down to the lab for us when things get busy." She then hurriedly gave me some directions, and asked me to go ahead and take the tubes on down to the lab.

As I was putting on a pair of latex gloves, the clerical employee leaned in towards me and said, "You might want to throw on two pair - the woman you were just watching is HIV+; it's on her chart here."

It struck me a little bit to hear this, if for no other reason than to know that only a few millimeters from my fingers was a virus that is known by practically everyone, a virus that is father to an extreme amount of controversy. It was also the first time I had ever looked at an individual and known them to be HIV+. As I was having these thoughts, a curious thing happened. For a reason I do not know, the clerical employee continued to give me information about the patient. "Yeah,.....she's from Checksville, just up the road. I've seen her working in that little used book store. I've seen her kids in there with her, but I heard she was going through a divorce right now. It's probably the result of this right here," she pointed to the tubes of blood in my hand.

Why did I need to know this? I did not see any usefulness in knowing this, and it felt very gossip-like as I listened to her half whispered voice. I just nodded back to her, and headed to the lab.

After I had dropped off the samples at the lab and was walking back to the ER, I began to really think about the information that had been given to me. It seemed strange to me that I could just show up at a hospital, acquire a position as a pre-med volunteer, work for only a few days, and then have it so freely made known to me that the woman who runs the bookstore in Checksville is HIV+. It seemed like an infringement on the patient's confidentiality; it certainly felt that way. Perhaps I had already been accepted as part of the ER team and was thus eligible to know such information. Yet, I kept asking myself: Did I for some reason need to know that this woman was HIV+, as a student

volunteer? I was in no danger at all when I carried the blood samples to the lab. Following the guidelines of universal precaution served as protection enough. Furthermore, did I need to know that she ran the bookstore? I have noticed in hind sight, especially from my experience in surgery, that health care workers will often spread the word that "case 3 is dirty," or "room 337 is positive." The intention is to make everyone aware so that protection may be maximized. Spreading the word is simply an extra alert. But universal precaution denotes that every patient is assumed to be an infected patient. Therefore, the health care worker is *always* protected, and extra warnings should not be necessary. Yet, it is almost always made known to a good number of people when it is discovered from a chart or directly from the patient that HIV is present.

That particular day, I was confused. Today, I feel as though I have my opinion of that experience well polished. Is it acceptable to tell coworkers to be a little careful because you know patient #7 is HIV+? I think so. This is not information that cannot be taken from the chart by almost any physician, nurse, or orderly who sees the patient. There are some facts that it just makes good sense to be aware of. Awareness maximizes safety beyond universal precaution. It does not take an individual working in a hospital long to learn that a lot of people skimp on protecting themselves. It always seemed to me that these people were assuming the patient to be HIV negative, rather than HIV positive. So, having knowledge of an HIV infection does seem to have some utility. But, what about the information I was given about the patient's workplace and family life? I feel it was wrong. There is nothing to be gained by letting others know where a patient lives or works, and there is certainly no utility in revealing facts about personal matters. I suppose I have adopted a philosophy about the communication between workers such as secretaries, LPN's, nurses, and orderlies: Only the information needed for getting things done in the hospital should be discussed and allowed - the rest seems like a violation of privacy. I know it is assumed that hospital employees will not discuss patient matters. Indeed, several people I encountered upheld a strict policy of refraining from

conversations about patients. But, I learned rather quickly that not everyone respects patient confidentiality, and it was frustrating.

I had another experience in the ER that, although I still cannot decide if something was done wrong, I do know that what I saw seemed very strange to me at the time. A tall, thin man who couldn't have been over 35 came into the ER with complaints of severe headaches. From listening to the nurses, I quickly gathered that this man was a frequent visitor of the ER. The physician spoke with the man for some time as I organized one of the other examining areas. Then, I turned around, and he was gone - wheeled from the ER. It was told to me that he was being taken to radiology to have his head scanned. I assumed there must have been enough suspicion about his recurrent headaches to go ahead and have a thorough look.

About an hour later, the young man was back in the ER, where he sat quietly in his assigned examination area. He sat behind the curtain for what seemed like a very long time before a young lady came into the ER and dropped a large folder on the desk. A radiologist followed, and he picked up the folder and began to talk to the ER physician about its contents. I listened to the conversation, and looked at those pictures with them (or rather I listened and stared at a mirage of images that looked like ink blot tests). A nurse pulled me away from the conversation and asked me to put some of the patient's information into the computer.

As I sat at the terminal, a very eerie feeling overcame me. I now knew this man's situation, and it was not good at all. From what I had gathered from the physicians' conversation, his scans showed a sizeable brain tumor and several other lesions. A chest x-ray also showed evidence of cancer. My feelings of awkwardness were triggered by something I had heard the physician say as I sat down at the computer, "He has no idea that he is eaten up with cancer." I began to type this information into a computer. As I continued to plug away, I would occasionally look over my right shoulder and see this

man. He continued to patiently wait - waiting for someone to tell him to go home, or "take this prescription, and get it filled soon." It was indeed a strange feeling to know that a person sat in the room with me, thinking he was having migraine attacks, while at the same time I continued to type into a computer information about his cancer.

Things remained this way for a while: the physicians continued talking, I continued typing, the nurses continued working in other areas of the ER, and the patient continued waiting. Finally, the physician stepped behind the curtain, and everyone in the ER seemed to get a little quiet. I looked at the somber faces of the nurses who stood around the desk. It seemed that we all knew that a man was having his entire life changed only a few feet away from us. The physician stayed behind the curtain for 16 minutes (I was watching the clock). Nothing could be heard, no screams of denial, no expressions of anger, no crying - just the dull hum of conversation, too low to be understood. The physician eventually stepped from behind the curtain, and sighed deeply. He walked straight from the ER towards the lounge. I didn't see him again that day.

A nurse then went and pulled the curtain from around the patient. He sat upright, staring blankly at the foot of the bed. Now, when I looked at him, I knew he knew. My strange feelings did not dissolve however. Instead, they became mixed with those of empathy for the man who sat near me, just having taken a huge turn in his life. It was as I stood in the ER having these feelings that something happened that was puzzling to me. The man spoke his first words since the curtain had been pulled back.

"I need to talk to my wife," he said in monotone as he continued to look at his feet.

A nurse picked up the desk phone receiver, stretched the cord across the ER, and asked, "What's the number?"

I was shocked. I had to bite my tongue to keep from suggesting, "Why don't you let this guy go into the lounge or triage area? He just found out he's got brain cancer for goodness sake."

The patient was surprised by this as well. He sat silently for a few seconds, holding the phone receiver. Then he softly said, "I think I'll just call later, or go on home now."

I was emotionally stirred and upset. There seemed to be a lack of attention to the patient's privacy. I cannot imagine trying to tell a loved one that I had cancer while a group of strangers listened, and perhaps watched. I feel there should have been a greater effort to provide this man with the opportunity to talk with his wife in private. Perhaps the man simply changed his mind - decided to wait to talk to his wife. I do not think this is what happened. If it was, there still should have been more energy put into his request to call home.

After having spent the time I did in the ER, I realize that privacy is not always a priority. The priority is to treat efficiently, effectively and rapidly. Yet even today I still feel as though confidentiality was breached with the HIV patient. I also still have strange feelings when I think about the cancer patient's requests to talk with his wife, and how these requests were handled. I feel sorry for him.

Futility

Anencephaly is a lethal birth defect that affects a few thousand newborns each year. This congenital absence of a skull cap and upper brain leaves the child unable to feel pain and with no chance for extended survival. However, the existence of a brainstem in these infants allows for a heartbeat and respiration independent of machines. It is often the case that early detection of this grotesque disorder by the use of ultra sound leads to a termination of the pregnancy. Yet, a number of anencephalic infants are born each year, and the issues that sometimes follow are emotion riddled and very intense. Several questions develop when a child like this is born. Should the child be aggressively treated? Should the child be treated at all? What if the parents' desires conflict with the doctor's notion of futility? Can money be better spent on others? And , is it acceptable to harvest organs from these children? These are but a few of the questions that families and physicians must answer.

For a reason that I am not quite sure of, I have been drawn for sometime to the issues raised by a viable birth of an anencephalic child. I vividly remember the first time I learned of anencephaly and the uncertainties about its treatment. It was just two years ago when I read a newspaper article by Dr. Frank Boehm. The article described the care of "Baby K," an anencephalic child born to a mother who was insistent that the infant be treated, to the point of initiating artificial respiratory therapy. At that particular hospital it was deemed as a futile effort to initiate and continue such costly measures for an infant that had zero chance for a life beyond a few months. Yet, after legal litigation, a judge ordered that the infant be treated in accordance with the mother's wishes. Baby K, as a result, was sustained for 1 year at a cost of one million (and at the time Dr. Boehm wrote his article, was still being sustained).

In another of Dr. Boehm's articles he describes the effects of one particular father and mother to have their newborn anencephalic child's organs donated to help others. The judicial system, however, would not allow this since an anencephalic child does not meet the criteria for whole brain death. It was supposed by the judiciary that to take the organs from the anencephalic child would be, in essence, taking organs from an individual who was not yet dead. So, as a result, the anencephalic child's organs were not taken for transplantation use, and therefore became unsuitable upon the infant's natural death.(13)

I had read these articles, as well as several other writings about anencephaly, when I decided to go visit Dr. Boehm. I made attempts to arrange a meeting with him, and two weeks later, on a Monday morning, I sat outside of Dr. Boehm's office. I remember how intrigued I was by the opportunity to speak with a physician who had seen and dealt with this bizarre thing called anencephaly.

"Hey there, I'm Dr. Boehm. So you want to talk about anencephaly huh?" he said as he finally poked his head into the room.

"Well, talk and learn," I responded.

Our conversation moved into his office, and we spent some time just talking about medicine in general. Eventually, I began to get at the subject I was most interested in that day.

"Well, Dr. Boehm, I have several questions to ask you. I hope you will feel free to answer candidly," I said. Turns out this was not a problem at all. I continued, "I have read your story about Baby K. I found it to be very interesting. I wanted to ask you: What do you think should be done when, say, insurance will not cover the cost of treating a child like this, but the parents insist.....you know, a case like Baby K's?" I asked.

"Nothing....Literally. The anencephalic child has NO chance for survival.....zero," he said. His tone then immediately shifted and he asked, "Have you ever seen what these children look like Derek? Have you ever looked at a picture of one of these hideous looking infants?"

Before I could answer, he was shuffling through a stack of books and papers. He quickly set in front of me an array of pictures that would cause almost anyone to wince.

"We usually wrap a towel or blanket around the head so the parents don't have to see," he told me.

I could see why. I wanted to tell him this, but I was frozen looking at those pictures. I reminded myself of the child who stares at a horror movie, knowing that later at bedtime he will be scared, but still unable to look away. The pictures showed grossly malformed infants with literally no skull. There were only the semblances of protruding eyes and other facial features on a shelf of flesh that sat atop the neckline. My emotions were considerably jostled by the pictures, as I am sure was Dr. Boehm's intent. I soon tore myself away from the pictures, and I was able to continue with the conversation.

"I wonder, do you think it might be worth the gratification it would bring the insistent parents to go ahead and treat these types of children?" I asked. I was searching for some reason to treat these children.

I received a very interesting answer. "It is not a perfect world. The medical arena has limited resources and this must be considered in combination with what is futile and not futile. Baby K absorbed \$1 million in health care money during her one year stay in the hospital. According to the Tenn Care plan, it only takes \$8 million to treat every single bone cancer infant each year," he said to me. This put the outrageousness of Baby K's medical expenses in definitive perspective.

"Wow," was all I said in response - it was all I could say. One hopeless child had absorbed an eighth of the money necessary to treat several children who have a chance for survival.

A thought then struck me. "Well what if you took all of the dollar signs away? What if money were not in the picture? Would you, as a physician, be willing to devote your time and energy into helping these children, and in a sense, their parents?"

"No," he said without hesitation. "These infants need a new head, a *new heaa*....that's all that would save them, and we cannot provide that."

That seemed about as sensible as it could get to me. There was no way to argue this point, as mankind has yet to develop a head transplant procedure (and never will!). I changed my focus to the concept of euthanasia, and asked, "What do you think of the following statement: You are killing a child when you do not treat an anencephalic child after birth?"

"To 'kill' brings up very negative images. You must remember that these children have no chance for survival at all. All medicine can do is prolong the time it takes for these monsters to die," was his reply.

It was crystal clear that Dr. Boehm did not believe in the aggressive treatment of anencephalic children. In fact, he responds in one of his articles to the notion that society must find a way to treat every condition, even if futile. His response is a poignant, "You write the check." (14) Does medicine have the responsibility of protecting and prolonging the lives of children with no hope for a future at all? Absolutely not, according to Dr. Boehm. I left the office that day feeling convinced that anencephalic children should not be treated. I could not find a way to make sense of treating a child only to extend the life for a very short time. Even if the parents are demanding treatment, it seems like a wasted endeavor.

I continued to think about this issue over the following weeks, even though I had come to a rather certain conclusion. Perhaps the fact that I am not used to drawing an ethical conclusion so quickly would not allow me to do so with this issue either. I do not know. Nonetheless, I continued to mull over the topic and read the opinions of others. Here are two of those findings:

"When there is no therapy that can benefit an infant, as in anencephaly or certain severe cardiac deformities, a decision by surrogates and providers not to try predictably

futile endeavors is ethically and legally justifiable. Such therapies do not help the child, are sometimes painful for the infant (and probably distressing to the parents), and offer no reasonable probability of saving life for a substantial period." (15)

"The Child Abuse and Treatment Act defined as child abuse the 'withholding of medically indicated treatment' from children. However, three conditions are recognized under each of which life sustaining treatment is optional.

- 1) The infant is clinically or irreversibly comatose
- 2) Provision of such treatment would merely prolong dying or not be effective in ameliorating or correcting the infant's life threatening conditions.
- 3) Provision of such treatment would be futile and the treatment would be inhumane." (16)

Clearly, all fingers were pointing toward a policy of not treating the anencephalic infant. In fact, I could not find a single piece of writing that supported the treatment of these infants. All of the information I could find was sensible, so I decided that my initial agreement with Dr. Boehm was correct. I have come to believe that a policy should exist whereby any child born with anencephaly should be allowed to die naturally, and without any heroic measures to extend life. There are a couple of other considerations however: Should the anencephalic child be viewed as a potential organ donor? Also, should the anencephalic child be euthanized upon birth, given that it is destined to die anyway?

I feel as though I approach the first of these questions, that regarding organ harvesting, as a Utilitarian - action should be taken that is most beneficial to the largest amount of people. Organs should be taken, with parental consent, from the anencephalic child so that other treatable children may have a chance. This is the same policy I hold with adult donors too. But, when considering anencephalics as potential donors, there is a wrench in the works. This country upholds a dead donor rule stating that no organs may

be taken from one individual for the betterment of another individual, unless the donor exhibits whole brain death. This certainly creates a bit of an ambiguity, since anencephalics don't even have a *whole* brain. It becomes impossible to meet the definition of whole brain death. But after some reflection, I do see ways around this. First, the definition of brain death could be altered so as to include at least one exception, the anencephalic child. Second, the definition of brain dead could be changed to one of cortical brain death only, thus qualifying the anencephalic child as "dead" from the start. Both of these seem to me to be logical approaches to the avoidance of wasting viable organs and saving infant lives. In a conversation with a roommate, I once made an analogy about trains. Ten box cars would not sit unused on a track if the engine was destroyed; the cars would be used elsewhere. They would be moved to another engine. Why not the same with the organs of the anencephalic child, a broken engine? Granted, the analogy is void of the emotions involved when parents unexpectedly give birth to a deformed child, but an analogy of practicality nonetheless.

With such an approach to organ donation and an acceptance of futility, I dwelled on the possibility of euthanasia for a very short time. If it is accepted that treating an anencephalic child is pointless, then it is just as pointless to allow them to sit in a hospital for two or three days until they naturally die. If for no other reason, the hospital stay soaks up funds better spent elsewhere, like transplant surgery (and saving money is one of the big considerations when deciding to forgo aggressive treatment). I wondered, why not maximize the savings and have the child expire as soon as possible? "Infanticide! Infanticide!," some may scream, but if the parents are willing, there is no reason to refrain from effectively euthanizing the child and viably procuring organs. I cannot find a way to believe that ceasing the ephemeral heartbeat and respirations of the child is somehow comparable to murder. I remember the question I asked Dr. Boehm that day: "Are you killing the anencephalic child if you take him or her to the OR just after birth, instead of five days later when the child 'dies' on its own?" I must believe that the answer is no. An

appeal may be made that if the child were normal, to take it to the OR for organ procurement could easily be called killing. Why not with anencephalics? For me, the answer lies in potentiality. The normal child has the potential for a normal life prior to a hypothetical trip to the OR; the anencephalic does not. I suppose this is the working definition of medical futility. Anyhow, the possibility of putting the label of murder on euthanizing the anencephalic child becomes impossible if the definition of brain death is changed to cortical brain death. In this case, the child qualifies as a still birth. What about the possibility of a difference in moral consequence between *letting* the child die in a few days, and actively ending the life at a chosen time? I cannot understand a difference between the two. In each case something is being done, it just that when passively euthanizing the child (letting them die on their own), the something being done is *nothing*. *In* other words, when you do not treat, you are actively making a decision to do something - namely, nothing. So I feel there is not a valid difference between letting the child die over three days, or bringing about the child's death in only three minutes. The anencephalic child certainly does not know the difference.

As with several of the issues I have addressed, I suppose communication to be one of the main factors in relieving some of the intensity associated with the live birth of an anencephalic child. When I have considered the birth of these unfortunate children, I have tried to decide what might make decisions easier, as well as which decisions are ethically sound. It seems likely to me that a thorough understanding of the condition via parent/physician communication might have the ability to ease some conflict. Perhaps it is the case that the emotions of having a severely deformed child cloud the parents' ability to hear and understand the notion of futility. Likewise, a legislative acceptance and understanding of the fact that anencephalics have a zero chance for survival might allow for changes in the dead donor rule. This would perhaps lead to increased organ procurement. However, I do see that the acceptance of futility seems to be a difficult thing in medicine. I have seen that it is very hard for human beings to voluntarily let go of

a spouse with a terminal disease, siblings who are dying, and certainly newborns with lethal defects. I suppose that sometimes what is logical and reasonable cannot be seen due to the blinders of love and emotion.

The culmination of my experience with anencephaly and the corresponding issues takes the form of the following protocol, which I feel should be followed: First, the parents should be made aware of their child's futile state. Then, the possibility of organ donation should come up. If the parents agree, take the child to the OR. If they do not, (and this is where my position differs from that of many), the child should be euthanized relatively quickly. Insurance policies should not support sustaining the child.

"Leave Me Alone....I'm Burned!"

Anyone who has ever considered the possibility of being severely burned or burned to death has most likely shuddered at their own thoughts, and rightly so. Being severely burned seems to be one of the most physically painful things a human being can experience. Recovery takes a long time and usually involves multiple "tankings" where infective burnt flesh is removed, painful dressing changes, and the emotional distress associated with the accompanying disfigurement. I have often wondered, what makes a person keep going in such a situation? Would I be able to fight my way through severe burn recovery? I sometimes think that I might not be able to do it - if it happened to me, I might want treatment stopped.

These personal thoughts are representative of a big issue with severely burned patients: Does the patient have the right to refuse medical treatment that if stopped, will certainly lead to death? And, is a burn victim lucid to make such a decision? I have juggled the components of this issue in my mind for some time now. It seems questionable to assist a patient in his or her own death when survival is certainly possible. But, it is down right horrifying to think that others have the power to decide how much pain is worth enduring to sustain life, especially when the life in question is not their own. Often times it is the case that a severely burned patient is judged incompetent to make personal decisions because of the extreme pain and accompanying drug therapy. The patient's judgment is presumed to be clouded by the thick haze of constant discomfort and the effects of narcotic medication. This is the portal through which a physician or family member is looking when it is decided to treat a burn victim against his or her wishes. Those who support the right of the patient to refuse treatment, at any time throughout the treatment, do not seem to believe in the judgments of incompetency. They rather feel that the patient remains autonomous, and this autonomy is to be upheld throughout therapy.

When I initially began to think about this issue, I had no idea which category I fell into. I knew that deciding how I felt about this issue was going to be difficult for me.

I began to read about one of the better known and exemplary burn victim cases. It is the case of Dax Cowart. In brief, Dax Cowart was an active, athletic young man who suffered severe burns during a 1973 propane gas explosion, the same explosion that killed his father. Dax was left with 65% of his body severely burned. "For Cowart, there were countless tankings in solutions to cleanse his wounds, procedures to remove dead tissue, the amputation of badly charred fingers from both hands, and the removal of his right eye. The damaged left eye was sewn shut. And there was terrible pain." (17) Dax lived through a very lengthy hospital stay, throughout which he begged to be killed, or at least given the opportunity to kill himself. Yet, it was believed by physicians that Dax was incompetent to make this decision, and his mother would not allow it due to her deep religious convictions.

As I have read about Dax's case, I have been horrified by the images produced in my head. However, when I went and watched video footage of Dax's treatment, what I envisioned took a back seat to the reality of Dax's horror. It was difficult for me to look at the monitor as the severely burned man screamed throughout his tanking. I was difficult for me to look at a film shot from a camera positioned on the disfigured face of Dax Cowart. It was also difficult for me to believe anyone should have to go through such a thing if they did not choose to do so. I know that Dax did not choose to be burned, and his story and the film footage made it very clear that he did not choose to be treated.

But Dax was treated against his wishes, and he ultimately recovered and survived. He is blind, crippled, severely disfigured, without the use of his hands - married and practicing law! This is where it becomes difficult to believe that Dax should have been allowed to die. He managed to find love and a relationship and graduate from Baylor Law School, despite his obvious and formidable barriers. When I first learned these aspects of the Dax Cowart case, I remember thinking that the right thing must have been done. Dax

survived and became an interactive productive human being again. But Dax still claims that he should have had the right to end his treatment and die back in the 70's. This is the barb that keeps the questionable ethics of Dax's case from sliding off the hook. It seems that if Dax was nothing but happy and grateful to be alive, then it would negate the disregarding of his constant pleas to be killed. It would make it seem acceptable that he had been forced treatment. But this was not at all the case with Dax, and this left me confused.

I began to seriously ponder what should be done in a case like that of Dax. I could see both sides very clearly. It made sense that severe pain might make a patient wish he or she was dead at that moment, but not for ever. Wishing for death might really be a wish to stop the pain. I could also see that a personal value judgment might involve concluding that the life of a blind crippled, disfigured invalid would not be worth months of excruciating pain. I decided to look burn treatment right in the face, and I made arrangements to spend some time in a burn unit. I was hoping to see or hear something that might make it clear to me what should be done in a case like Dax's. I saw a lot and heard even more at that burn unit -almost too much for me to absorb in such a short time. The day started with the burn unit clerical worker.

"Come on with me, and I'll show you around the place," said Judy, a pleasant woman who had been working in the burn unit for several years. She lead me to a storage room at the back of the six bed burn unit. "Now in here is where we keep all of the supplies...things like special blades for surgery, other sterile instruments, and oxygen tanks." She then showed me an array of strange looking tools and knives used to cut and manipulate the skin of burn victims.

"This unit has its own OR, right here," she continued as she pushed the OR doors open. Inside was a small surgery suite with everything ready to go. "Why... we even once delivered a baby in here! The woman had about a 70%, and was pregnant. All the og/gyn guys came down here and delivered that baby. You see some pretty crazy things around

here sometimes," she told me with a smile on her face. (I think she was rather proud that they had successfully delivered a baby from a burn victim. She should be.)

"How did the mother fare?" I asked.

"Oh, she did fine. It was a very painful thing though. And, it added to the difficulty of her recovery," she replied as she lead me across the corridor. She stepped up to another set of double doors, and pushed them open. "In here is where we do the tankings....not a very fun place to be."

In the room was a huge hour-glass shaped, stainless steel tank with a sling hung from the ceiling above it.

"We have to pour this stuff in there and scrub'em down," she said.

"Does it ever get old having to see so much pain?" I inquired.

"Well, it was hard for me at first. But after a while, you get used to it; you start to realize there's just not much else you can do for these folks. You just let'em scream," she replied.

I stood there for a moment at those doors and looked at the tank and its surrounding tile walls. I thought of the pain I remembered seeing in the Dax videos, and I wondered how many times the same thing had happened in that room. I wondered how many people there were that considered that room a little portion of hell on earth.

I broke myself away from my thoughts, and said to Judy, "Tell me about the patients here now."

"Well, we have five patients here now, and six beds," she said as we walked towards bed #1. "Number one, here, is an overflow patient. He hasn't been burned. Number two is a bad case....he passed out and fell head first into an electric heater. His head burned down to the skull, and even into the bone itself. He has a lot of family support, but he is just about too old to survive this kind of injury. I think they've done four or five skin flaps on him already."

I looked into room two, and saw an old frail man with a thick wrap of bandages around his head and over his right eye. He sat upright in a chair, staring off into space with his one good eye. He looked drugged.

Judy continued, "Number three fell asleep in a chair and was smoking at the time.. He caught on fire, and was not able to move fast enough to put it out. His 90 year old mother died trying to help put out the fire; she burned to death. I'd say he is in his late 60's, and he's about a 65% burn."

I gazed at the man's huge swollen torso and groin, and also noticed his hands. They looked like baseball mitts they were so swollen. He lay silently on the bed, his face pointed toward the ceiling above.

"Number four is a 57 year old woman who got burned trying to throw out some ashes from her fireplace. She had a pretty bad burn, but was doing fine until just about three days ago. Her kidneys suddenly gave on her, and now she is on dialysis. Kidney trouble happens quite often with these serious burns," Judy explained.

I looked at her and noticed her raw legs. She was asleep.

"Are those graft sights, there on her legs?" I asked.

"That's where they had to take some good skin to put on her burns."

The places on her legs looked as bad as her burns to me.

"The last patient here is this young man in bed five. He claims he got burned trying to light up a kerosene heater, but he has an extensive drug abuse record. A lot of the people around here suspect that he got burned trying to free-base. He's about a 70%, and he has a lot of upper body burns - face and neck. He's already had three surgeries, and he is on a ventilator. Sometimes he will respond to you.....he can probably hear us now. Number six there is empty."

I watched the young man squirm in his bed for a little while. He was expressing more pain than anyone in the Unit. I eventually stepped back over to the nurses' station with Judy, and we began to talk.

"What do you think about all of the patients here? Should all of them be here, being treated?" I asked.

" Some people that come here are going to die, no matter what. Like number two there; he won't make it. He's just too old. The other people who make it go through a lot to make it," she answered.

"What do you think you would do if you were that man's doctor, and he asked you to quit treating him for his burns?" I asked Judy.

" I'd probably want to go ahead and let him go; quit treating him. I remember one particular patient down here that really made me realize that these patients know what they want. She was burned very badly, and was refusing to have surgery. The family said to go ahead and schedule the surgery, so it was done. On the day of that surgery, that girl willed herself dead, just before she went into the OR! I guess she got what she wanted," Judy shared with me.

Judy suddenly had to leave for a phone call, and our time together ended. I took a seat at the nurses' station, and gathered my thoughts. I reflected on what I now knew about each of the patients there. I took some notes, and then began to watch what was going on around me.

I was looking for people that I might try to talk to, and I noticed Lindsey. She looked very comfortable, and seemed to be a decision maker. I introduced myself, and we began to converse. She had been working there for three and a half years.

I cut to the chase with Lindsey, "What do you think about people in here who don't want to be treated, the ones who refuse to cooperate?"

"I think that the line on who is and is not aggressively treated has everything to do with age. A 95 year old woman who asks to have treatment stopped has a much better chance of having her wishes granted than does a 25 year old with the same burn. I think these patients often have the ability to make their own decisions, but it's a very case-by-case thing," Lindsey said to me.

This made relatively good sense to me, but I wondered what was to be considered in each case. Was there a ruler for measuring competency, and a cut off point to go with it? Lindsey hurried off before I could ask her these questions. She scurried away from me saying, "Being burned is a terrible thing....having to go through it is just not fair, it's just not fair."

I got the feeling that Lindsey was frequently disturbed by the issues she faced as a burn unit nurse. She seemed like the type of person who steered clear of tough issues by staying very busy. I did not get the chance to talk to Lindsey again.

After the short conversation with Lindsey, I decided to watch for a while, instead of talking to anyone. During this time, I was asked by a nurse named Sarah if I would like to help with a dressing change. I changed into scrubs, and put on a mask and gloves. We headed for bed three, the cigarette burn victim.

"Mr. Jones.....we're going to change those dressings for you. It should only take a little while," Sarah said loudly as we approached the bed. She and another nurse pulled out some kick buckets for the old dressings and threw around a mirage of packets, bandages, and medicines. Mr. Jones was unrobed, and I almost left the room. I had never seen such an injury. Mr. Jones's lower abdomen and groin was so severely swollen, it was hardly recognizable. The tendons in the back of his enormous hands were exposed, and he had several gashes put in his legs to relieve the tension of the swelling. I handed the nurses a few things here and there, but I just watched mostly, and tried to adjust to Mr. Jones's appearance.

"Mr. Jones, we'll be finished in just a few more seconds pal, " said Sarah

"Is he awake right now?" I asked. I had not heard a peep from Mr. Jones, or seen him move at all on his own.

"He sure is....aren't you Mr. Jones?" Sarah said as she placed several yellow strips across the small of his back. Eventually, Mr. Jones was bandaged up again, and rolled back over on to his back. I stood by the bed and looked into Mr. Jones eyes as he stared

upward. He blinked. This was the only sign I had seen that a person was really inside that horrible body. I became a bit emotional after this, and it must have been obvious. Sarah asked if I was doing alright. I said I was fine, just lost in some hefty thoughts. I slipped away after telling Sarah I would like to talk with her after I got me something to eat.

As I walked to the hospital cafeteria, I refocussed on my goal: to try and figure out if a burn victim is lucid enough to refuse treatment, and is refusal acceptable. At that point, I was not much further in forming my opinion, but I did have a more vivid picture of what it was to treat burn victims. I cannot say that I enjoyed my lunch that day. Thoughts sometimes have a way of destroying an appetite. I picked at my food, and eventually headed back to the unit. Sarah was waiting for me.

"Ready to talk?" she asked in a bubbly voice.

"I think so. Why don't we go back to the TV room, where there are fewer disturbances," I suggested. The nurse's station was buzzing with activity, and I wanted our conversation to go uninterrupted.

In the TV room, I asked Sarah the same basic question I had been asking everyone, "What kind of competency do you think these patients have? Are they capable of deciding their own treatment process?"

"These people don't do anything but hurt. I don't see how they could be lucid. It's pain 24 hours a day for them," she replied.

"Well, what would you do with a patient in the ER who is severely burned, but is stoutly refusing treatment?" I returned.

"Just sedate him, and take him on in," was Sarah's reply.

This was somewhat shocking to me. I felt myself leaning for the first time towards supporting the burn victim who did not want to go through treatment. It seemed too harsh and paternalistic to "just sedate him and take him on in."

Sarah continued, "They are not aware enough to weigh the pros and cons of such a decision, because of their pain. I guess I feel like, 'If you want to end your life, fine.....but don't ask me to do it for you!'"

Clearly Sarah felt she would be a moral participant, and in the wrong, were she to grant a refusing patient his or her wishes. I continued to question her, "What about the patient who says to you, 'I never asked you to start treating me in the first place!'" With this comment, my thoughts moved to the Dax Cowart case, and how he had asked a farmer to shoot him at the explosion site only minutes after his burn.

"Well you see, once treatment is begun, it is hard to back off," was her response to this question. I was not especially satisfied with this answer.

We talked a little while longer, and Sarah went back to her duties as a Burn Unit nurse. Something about Sarah's attitudes bothered me. I don't know if it was her beliefs, or her rather staunch delivery of these beliefs. In either case, I found myself defending the burn victim's right to die as I spoke with Sarah. Perhaps I was working my way towards my own belief.

The day progressed to evening, and I continued to watch. A new patient was on his way to the unit. From what I could gather, he was a construction worker who had suffered a serious electrical burn on the job. Apparently, a live wire had fallen on the back-hoe he was operating. He came to the Unit, and I watched his first tanking. He was clearly in pain, but he did not seem to react as badly as one might expect from looking at his injuries. Perhaps he was already medicated, or in shock - I don't know. Before long, he filled the vacancy in bed six. I wondered if his competency had been washed off in that tank with his burnt flesh. I wondered if I had just watched someone lose all autonomy. I left the room, and he said, "See you later" as I walked away. I nodded back, and told him to take it easy.

Individuals were now gathering in a conference room adjacent to the Unit. A monthly group support meeting was being held for burn victims. I had been invited to join

the group, so I took my place in the conference room. In the room were three gentlemen who had survived serious burns. One man was alone, and oddly enough was celebrating the three year anniversary of the night he suffered a 70% burn trying to save four horses from a burning barn. I'll call him Marcus. The second man, Ted, was the survivor of an electrical burn and was there with his wife. The third member of the group, Brian, was still recovering from a plane crash five months earlier. His wife tended to him as he sat in a special reclining wheelchair. I sat in the circle with these five individuals and two of the nurses. The conversation started with Marcus.

"You know, I used to have some horrible dreams when I was back here in this unit. I used to dream that I was a World War I soldier and I was trapped in a pill box with hundreds of other guys. We were all squished up together. There was one little air hole at the top of the pill box, the only place to get air. I climbed my way to the top and put my lips to it. As I breathed, I could feel the other guys trying to pull me away from the hole. Eventually they would quit pulling, and I would stand there on them - still breathing," he said.

Ted spoke next. "I used to have'em too, man. In mine people were always after me. I was always being chased or hunted down like an animal. They were bad, buddy. Almost too real seeming to handle. And long! Boy, it would seem like those dreams lasted forever. You get where you can't tell reality from your nightmares."

I began to wonder if the drugs did have such an effect that these patients could not make sound decisions. If these dreams were so real and lifelike, not to mention traumatic, it had to do something to the person's frame of mind. As I was thinking this, Brian added that he had experienced a few bad dreams, but none so vivid.

With this, the dream topic dwindled, and Brian began to ask Ted and Marcus about the speed of progress. He asked first about weight gain. He was concerned about this, and I soon understood why. Brian weighed 220 pounds before his accident, and he now weighed 134 pounds - he is 6 feet and 3 inches tall. Brian's questions hinted that he

was still learning to cope, but his attitude seemed extremely positive. His wife shared the same enthusiastic positive attitude. In fact, the two were so positive that I had to question their sincerity in my own mind. Brian then shared that he was beginning to use his hands again. He had held a spoon between his thumb and pinky finger for the first time that day. He seemed delighted with this progress. He continued to share with the group his personal triumphs of recovery, all of which were things the normal individual does every day. When Brian would say things like, "I don't like to look at myself in the mirror yet; I've only done it once since the accident," Ted and Marcus would nod in agreement.

Brian eventually quit talking about his recovery, and he looked at me. To this point, I had not said a word. I was just listening. Ted spoke up and said, "You got any questions for us?"

I did, and although a little reluctant to bring up the topic with Brian there, I asked, "Did any of you ever feel like giving up, just throwing in the towel?"

The three following responses were very interesting. Ted calmly said, "No, no....I didn't like those damn tankings at all, but I never did think of throwing in the towel. But, man, I hated going to that tank. I would look forward to my surgeries, because that meant I couldn't go to the tank for a couple of days." Ted was conscious throughout almost all of his recovery. He can remember everything from day two.

Marcus then exclaimed, "I love this life, man. I'm glad to be here. When I got burned, I made a choice. I chose to go in after those horses."

Then I looked at Brian. His response was different. He paused for a few seconds, then he said, "I don't think so. I can still see and spend time with my beautiful wife, and that's reason enough to keep me going. But, I don't think I will be flying anymore."

I began to realize the array of approaches to life people take when dealing with an injury as severe as a serious burn. Ted certainly hated having to go through treatment, but gave me no clue that he even considered death as an option. He did tell me that he would often ask "Why me?". Marcus was a fighter who seemed to love the gift of life no matter

what. He said he never asked "why me?" because he knew why. He tried to save some animals, and in a sense took responsibility for his burns. Again, Brian still seemed to be forming his philosophy on why things had happened to him. I suppose things were still very new to him.

We all continued talking for a good while. I was asked what my future plans were, and I continued to question what burn treatment was like for them. Eventually a plastic surgeon, Dr. Williams, poked his head into the room and called my name. I had arranged to speak with him earlier in the day, but he had been caught in surgery. I said goodbye to Brian, Marcus, and Ted and left with Dr. Williams.

It was now about 9:30pm as Dr. Williams and I sat in a large conference room. I began to talk to him about all of the things I had seen throughout the day. I asked him the now standard question about competency and burn victims. He told me that he believed a burn victim was often competent to make decisions, and he had no problems withholding treatment at the request of the patient. He made it clear to me from the start of our conversation that he did not accept a policy that life is to be preserved, no matter what. Judgment of quality and future outlook were necessary. He shared the following story:

"About three months ago, a new patient arrived at the burn unit. She was in her 90's and had a 95% total body burn. She was absolutely burnt all over. I don't think her own family would have recognized her. I really could not believe she was still alive. Now... when I saw her, I did not even consider treating her. After speaking with her, I simply ordered that she be made comfortable. What would be the point of sustaining her for only a few days or weeks in terrible pain, only to have her kidneys fail or infection kill her? Survival at her age is unprecedented."

Once again there was a hint that age was the determinant of who is to be aggressively treated. I recalled earlier in the day when I had seen in a patient log the name and percent burn of one of the unit's survivors. She was a 29 year old with a 95% burn.

"The more experiences you have with patients like this, the more realistic goals become. You start to learn what is reasonable to expect in certain situations. You also start to learn to accept," he added.

I noticed Dr. Williams's pensive nature as we talked. I would ask him a question, and he would pause a long time before answering. These pauses sometimes resulted in nothing more than an "I don't know." I realized that answering tough medical ethical questions was something that might take years for me to do. Or, I might never be able to answer some of the questions I will have. Dr. Williams is a plastic surgeon who specializes in the care of burn patients, and he still is confused by some of the same things I am. In a strange way, it was comforting to realize this about Dr. Williams. His struggle to understand certainly made my struggle feel legitimate.

It was now very late, and Dr. Williams and I ended our day. For Dr. Williams, I suppose it had been a day similar to several others for him. For me, It had been a very eye opening initial experience with a very tough issue in medicine. He wished me luck as we departed in the hospital corridor. In my own mind, I wished myself luck in figuring out what I believed was right for burn victims. I walked to my car, and started the long drive home. It was pouring own rain, and I remember that drive well. I am an avid listener of music; I almost always have it playing when I drive , especially long distances. That night, I drove in silence, thinking intensely as I stared at the road through the windshield. I asked myself: Have I now figured out if it is acceptable to quit treating a burn victim who asks to have treatment stopped? I thought of Marcus's account of his extended, realistic dreams. I thought of Ted's statement that you "can't tell reality from your nightmares." I had to think that perhaps these dreams interfered with competency. Maybe Sarah was right. Maybe these patients should just be sedated and treated. After all, Marcus, Ted, and Brian all seemed happy to be alive, and I would bet that each of them asked a nurse to "quit it" or "please don't do that" during their treatment (I know for a fact that Ted did this quite often). Surely these men are now glad that their requests were not listened to.

Then I thought of Dax Cowart. He had asked constantly for the doctors and nurses to quit being his saviors. They never did. And although Dax survived, he has never stopped supporting the right which he was denied - the right to die.

I thought of Mr. Jones, and I wondered what he would tell me about the issue. I recalled Lindsey and her notion that age is a top consideration when deciding to withdraw treatment. I related Dr. Williams's story, and thought of his obvious and similar belief. I thought of Judy's subtle hints that death is sometimes best.

Eventually, I became frustrated by all of the confusion I was feeling about this particular issue. I tried to strip the issue down to its very core by asking myself if it was acceptable to let someone die in a hospital. This time, the first image that popped into my head was the young soldier from the film Johnny Got His Gun. I recalled how badly I wanted someone to kill the young, voiceless, limbless, sightless veteran. I wished for his death because death was a gift for him - it was the only way to end the pain. I recalled feeling the same way when I first watched the Dax Cowart videos. But, there are just as many people who years after their survival will "love this life, man!" So, what should be done? As Dr. Williams might say, "I just don't know." I turned the car stereo on, and I drove the rest of the way home.

Conclusion:

"If you don't ask and probe, even when it becomes decidedly uncomfortable, you won't know." Richard M. Zaner, Ph.D. (18)

The past two years have been a time of asking and probing for me, an attempt to know. When I began this project, I honestly had no idea what types of issues would be afforded by my experiences. I have had to keep my eyes open for those that somehow didn't feel right to me. I had to uncover the issues buried in the complaints shared with me. At times, I even sought out experiences in an effort to expose myself to certain arenas, like burn treatment. What then came was the most challenging aspect of the whole project - pinpointing what I thought. I have a firm grip on the fact that practicing medicine is going to be a difficult, personally trying, but rewarding endeavor. It seems to demand a great amount of will, will to search for answers to questions that have no clear answer. I have tried, through the experiences captured in these pages, to lay a foundation for what type of interactions are best for patients and what type of communication is most desirable for a patient/physician relationship. I have made an effort to form a framework for the lives I will become part of in the future. I have come to believe that it is just as important to be emotionally buttressed and have a belief about the issues in medicine as it is to know how many cc's of Versed a diabetic adolescent surgery patient is supposed to receive. In several conversations with other people, this is what I have called the "duality of medicine," the mesh of humanism and science.

I do not yet know much at all about the science of medicine - this is just around the corner now. But, I have seen the humanism involved in the art of medicine. When I reflect on my surgery experience, I feel quite certain that the OR team should have listened more intensely to Mrs. Reds and said less about Mr. J. I think of Al and how much I wish he felt differently about his relationship with his physicians. It is still frustrating to know

that he feels as though he was at times handled in an unacceptable manner. I think about a physician who, in my opinion, takes too lightly his right to disperse drugs. I wonder how many people could or have been hurt by him. I envision being sued by an individual who's anger and expectations are beyond reason. Then, I think of Mr. Blodget and I feel at ease.

I contemplate the struggle between the health care system and a distraught pair of new parents - a struggle over the life of an unexpected and severe birth defect. I see dollar signs going head to head with the gift of life and the intensity of love for a child. I think of Ellen at home, enjoying the love of a family that would not give up on her. Then I question in my mind how different that family would feel if they had only the memory of Ellen to enjoy. I wonder if someone should have given up on Dax Cowart. Maybe someone should have; I think so.

I think of a young man in the ER with brain cancer. I see him hand the phone back to a nurse, and return to his blank stare. I see the HIV+ woman working in the bookstore; she was just another woman the day before.

These thoughts on what is ethically sound are very fluid in nature, much like the concept of hope. Experiences and influences have been able to switch my trains of thought from one track to another. In some cases, this has occurred with relative ease. For instance, before I met Ellen, I stoutly believed in rigid adherence to living wills. It has truly been a revelation to discover that beliefs on what is right and wrong are so constantly at risk of change. Perhaps one day I will feel that Al was handled exactly right; his hope and morale needed to be protected and preserved. Maybe I will be willing to put my personal energy and time into performing surgery on the anencephalic child. Or, perhaps I will continue to painfully treat a burn victim who looks me in the eyes every day and begs for death. I am certainly willing to state that such adaptations of my beliefs are possible, if not likely.

Will the environment of medicine and the journey towards becoming a physician be partly responsible for any possible changes? Will an immersion in science for the next few

years alter my feelings? I do not yet know. But, now I have a ruler with which to measure the changes - and learn form them. I do know that I will not give up in my attempts to learn and see different approaches and angles. At the same time, I hope I will not allow compassion and empathy to fall into the shadow of technology and science. I want to know. I want to be a good physician.

NOTES:

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