SYLVAN STOOL LECTURE FOR SERVICE AND TEACHING

THE FUTURE OF MEDICINE: CARBON OR SILICON?

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When Sally Shott, our immediate past president, told me last year that the SENTAC Board of Directors had given me the honor of The Sylvan Stool Award for Teaching and Service, I didn’t believe her at first. I was shocked. And then I immediately panicked and have perseverated over my talk “on any topic of my choosing” ever since because I really didn’t know what I should talk about.

So I thought, why was this award given to me? What could I possibly say that would reflect what I know about the ideals of teaching and service as embodied by Sylvan Stool?

My interactions with Sylvan had occurred exclusively at meetings like SENTAC. Sylvan had a marvelous mind, a big heart and a good soul.

He had many wonderful qualities, but today I will describe only two of his legacies because they are important for my talk. First, I remember how proudly he recounted the story about his dyslexia and that he beat the “odds”. While he shared his story I heard this man say that we are all individuals and that the “odds” (also known as “statistics”) are not what determine our lives (also known as “outcomes”).

The second was Sylvan’s passion for teaching optimal otologic examination using pneumatic otoscopy, a task that too many clinicians now relinquish to a machine, the tympanometer. He reinforced my beliefs that every problem has more than one solution and that caring for patients requires us to look (and listen) carefully and critically, because biological variation is limitless and each patient is a new challenge.

With these initial thoughts in mind, I intend to leave you with a question which I believe will occupy much of our personal and collective resources over the next 25 years. And that is: What will be the New Medicine: Carbon or Silicone?

In the next 20 minutes I want to tell the stories of two patients (and share some lessons I have learned from them), discuss alphabet soup, give a mini-course in medical anthropology, and review an important new medical textbook, all in the attempt to begin to answer this question.
CASE 1

Autumn D. was born full term with severe microcephaly, micrognathia and airway obstruction. Her mother Vickie, inutero, knew that the baby was severely malformed and she was advised that her baby had a 99% chance of dying soon after birth.

Vickie later recounted, “Before she was born they prepared me for her death.”

But Vickie has lived a long time with her mother’s multiple sclerosis and Vickie has witnessed and believes that “God puts into us an incredible desire to live.” Thus, at birth Autumn was immediately intubated and put on mechanical ventilation. Vickie wanted everything done for her baby. After CT scans, MRIs, ultrasounds, evaluations by neurology, developmental pediatrics and genetics she was told that Autumn only had 30% of a brain and that without life support she would likely die. And even if she did live, her “quality of life” would be doubtful. Vickie requested that a tracheotomy tube be placed so she could take her child home. I was called to consult on this case.

When I first met Autumn, I was not all that keen on doing a tracheotomy thinking it futile to prolong the life of this baby with so little hope for a future. But her mother insisted. I must admit that this made me feel somewhat uncomfortable, because I could not see myself in her position or begin to understand her feelings.

But I overcame my hesitation and performed the tracheotomy and hoped that we could get Autumn off the ventilator so the family would have some time at home to come to terms with this sadness and their imminent loss. These events occurred 14 years ago.

Last month Autumn returned for her yearly surveillance endoscopy. She is an active teenager who goes to school, communicates nicely using sign, reads at a second to third grade level, and has an incredibly full life. She knows me, knows my role in her life, and always gives me a hug but only at the end of the visit. I am very happy when I see her and her family because she is a reminder that this patient defied all of my pre-conceived notions and all of the best available evidence at the time, and even now.
Why did she do so well? We really don't know. I suspect that we have all seen many cases (maybe 95% or more) which proved our initial predictions. But Vickie's conviction that only “God ordains the number of days we live,” sustained her and gave her the strength to fight for services, schools and anything else she thought could help Autumn. Are we to ignore these deeply held beliefs and desires because the best evidence available did not support her beating the "odds"?

The lessons I learned from this patient and family were: I don't know what I don't know. And much of what I think I know may not be true or only true for the “typical” patient, whomever that may be. But I do know that a lot of what I don't know is not going to be found in the scientific literature, evidence based medicine, and statistics. Parents will provide guidance, so listen with an open mind and let them help guide your care.

CASE 1
Hannah, at age 3 weeks, began to develop lower facial, lip and neck compound hemangiomas. Within the next several weeks, many more facial lesions developed and she started to wheeze. Not surprisingly she was found to have subglottic involvement. Over the next several weeks to months we tried heroically but unsuccessfully to avoid a tracheotomy.

Over the next several years, we managed Hannah with surveillance laryngoscopy and bronchoscopy and “watchful waiting” for the hemangiomas to spontaneously resolve.

When Hannah was age 3, Sandy, Hannah's mother and a pediatric ICU nurse, asked if there was anything more to do, because these deformities were not involuting as I had been taught and dutifully told my patient's mother would happen. So both Sandy and I independently began investigating alternatives to watchful waiting. We both learned of an otolaryngologist in Little Rock, Arkansas, who was taking a very different (and very radical) approach to these children. At Hannah's next visit, we were both delighted to find out that we had found the same person—Dr. Milton Waner. I encouraged the family to seek consultation with Dr. Waner and then, over the next 4 years, fought very hard to get more than a dozen “out of network referrals” for her treatments. About three years into Hannah's travels, Dr. Waner was giving a lecture on the subject of vascular birth marks at the annual Academy meeting so I went and listened. His thinking was original, resonated with my experience, but went counter to the information in the literature. I learned from him about the role of a variety of lasers, embolization, and surgical therapies, and witnessed the transformation of a horribly deformed child into this beautiful young lady.
Dr. Waner was very generous with his time and since 1995, over the subsequent 10 years, I spent weeks with him in Little Rock (or of late NYC) and in Buffalo learning whatever I could about vascular birth marks, one of the most misunderstood topics the pediatric otolaryngologist encounters.

The lessons I learned from Hannah, her mother, Sandy, and Milton Waner were that just because you don't know the answer to a problem, you never ever give up on a patient and accept an outcome that is just not satisfactory. And, if you look hard enough, you will more often than not, find an answer—perhaps in the literature, in your own mind, from a colleague, patient or family, or other (perhaps unexpected) person.

Now for some nourishment, ALPHABET SOUP:

Every few years another “revolution” in medical care is put forward. EMRs/EHRs, QA/I, TQM, QOL, CPOEs, six-SIGMA, RCTs, meta-analyses, algorithms, and lately EBM—Evidence Based Medicine.

The October supplement in the white journal (ORL/HNS) is an excellent overview of Evidence Based Medicine and Otolaryngology. I highly suggest that you all read it.

The author, Dr. Martin Burton who writes from the UK, reports that “evidence based medicine movement has been embraced as one of 15 most important milestones in the last 150 years.”

I must respectfully disagree with this assertion. While science and statistics have a very important role in medical care, the over-emphasis on the science of randomized controlled trials (RCTs) and meta-analyses tends to over-simplify the biological and social complexity and diversity that we encounter in our patients. RCTs may be useful in helping us make predictions (which are only best guesses given the “odds”) and meta-analyses may provide summary information (which may apply to a very small number of “typical” patients under the bell curve). But these types of studies have problems, too. They are inherently biased by their own design because they usually exclude so many of the children whom we treat.
Where on this bell curve does the individual patient fall? Who are the 5% of the population in a highly selected group of children will you see in your office who will not conform to this classic normal distribution? Many of them will not even be on the curve because they have been excluded. Each child has a unique biological profile which is necessarily set in a unique social and cultural context which cannot be captured by these numbers. The increasing trend to rely more heavily on rcts, meta-analyses and algorithms to drive (instead of support) treatment decisions detracts from the unique clinician-patient interaction. Similarly, the use of templated EMRs forces us to gather only that data which appears to be relevant. This approach, while increasing reimbursement and legibility of records, limits the collection of “extraneous” data and thereby limits the creativity and limits the critical thinking that that are needed to occur for successful one on one relationships with patients.

Are we becoming the “Stat Family of Clinicians?”

Burton lists 6 principles of EBM. Time does not allow me to discuss each one separately, but they are worth mentioning so we can begin to critically think about the premises upon which this newest panacea for the ills of medical care, are being built.

1. A scientific and systematic approach to the synthesis of reliable information has greater value than traditional reviews. Perhaps this is true if there is an experienced, thoughtful person doing the review).

2. Bias may be responsible for the results in an individual study. rcts are best for eliminating bias. (This has already been discussed).

3. Tragedy can result from paying attention to poor-quality evidence instead of good quality evidence. Tragedy usually does not result from poor quality evidence but rather from not paying attention to detail.

4. Clinicians need information, and they don’t get enough from the sources they typically use. This I will discuss in detail in a moment.

5. The medical literature is growing… and there is not enough time to read even the good stuff. There really is enough time to read the really good stuff.

6. Undesirable gaps and variation in practice exist. Variation in practice can be positive force as it mimics biology and leads to innovation.
I do want to discuss #4 in more detail:

Clinicians need information: “Clinicians get information from textbooks, journals, meetings, their colleagues, industry representatives, and elsewhere.”

What’s missing from this list?

How about the primary source, information from the patient? And think about how much of this information is communicated by observation alone and just a bit of knowledge of the patient’s environment.

Now for the Mini-course in Medical Anthropology. Medical anthropology is the study of the intersection between the unique biology of the human as it is viewed within the context of social, political, historical and cultural factors relevant to that individual or group. Understanding the nuances of the human in society through an anthropological approach is critical to an optimal patient/physician relationship.

Now for the book review. Against this background knowledge on medical anthropology, I want to introduce to you a textbook of medical care, “How Doctors Think” by Jerome Groopman. Dr. Groopman's writings may be familiar to those of you who read the New Yorker or have read his other books. He is a hematologist/oncologist at Harvard, the one located in Boston. His book is full of many fantastic observations and stories of doctors and patients that exemplify his point of view.

From this book, several themes emerge: 1. what we know is based on only a modest level of understanding of human biology. 2. our primary data must come from the patient and his/her family, 3) once the data is collected it needs to be framed and re-framed by the thoughtful physician him or herself, and 4) while specialized technology is vital unfortunately it too often takes us away from the patient’s story and concerns.
Next, he emphasizes something that might be difficult for the scientist within us, and that is that deductive reasoning does not work in every case. “Medical care is a human interaction between patient and physician…..within a context of a social system and as such it is not a commodity.” AND

“When physicians relinquish their own thinking and instead look to classification systems and algorithms to tell them what to do, they tend to ignore the individual characteristics of the patient.”

He devotes part of the book to medical errors, particularly those made by good doctors (and recounts the story of a world famous CV surgeon. This CV surgeon offers up the observation that errors occur when we have incomplete primary source data or when we rely on strict logic, algorithms, clinical pathways and the science that we think we know to be true.

Finally, Groopman states that “Patients and their loved ones swim together with physicians in a sea of feelings.” Manipulating information by asking a series of questions is not the same as letting the patient tell the story and impart their values, emotions, goals and choices which are consistent with their philosophy of life. The most challenging patients are ones that require us to overcome prejudices, stereotypes, and accepted thinking and to listen to how the patient is describing his/her problem. We need to draw out the patient and family so that their principles are incorporated into what we might offer that patient. Clinicians who care for patients as compared to those who care for the disease will find scorecards, classification systems, and other tools of measurement less helpful. Many of us here today are surgeons. We know that every case can be different and that no two patients are truly “the same”. This becomes only too evident when we encounter, for example, a healthy 6 year old undergoes a tonsillectomy. Despite lack of family history for bleeding, lack of or a personal history of easy bruising, and a complete and normal pre-operative coagulation evaluation, this child ends up in the emergency room in shock due to blood loss from a post-tonsillectomy bleed. Why?

Maybe because a recent meta-analysis article told us that NSAIDs are statistically proven to be as safe for post-tonsillectomy pain relief. But if that patient had an as yet unrecognized coagulopathy that didn’t show up on one blood test or that was aggravated by the NSAID due to his/her unique pharmaco-genetic profile? Statistically the recommendations are supported for the group, but clinically they may be too risky for the individual. So what is the new medicine?
This is carbon: a thinking, living, breathing human who devotes his/her life to the study of people and the study of health and illness. Someone who has intellect, intuition, pays attention to detail, thinks all the time, actively listens, responds to uncertainty, has psychological insight and cares.

This is silicon: wonderful tools that can organize vast amounts of information, retrieve facts and statistics rapidly, statistically analyze aggregate information, give a list of alternatives but is dependent on what information is put in and how the information is organized and interpreted, by carbon and water based people. Think about it.

How many hours have we spent learning how to manipulate our many new electronic gadgets? Have we spent as much time talking to and thinking about our patients? Have we spent as much time acquiring new skills in patient interviewing techniques, perhaps expanding the information that we gain from QOL surveys?

Earlier I asked “Where would we need to go to find out how to care for patients? I think the answer to that question is found within us. We need to recognize our limitations, and overcome them. We need to cultivate an inherent interest in the people for whom we have been privileged to care. We need to find teachers and mentors wherever we can. We need to recognize, acknowledge and overcome (to the best of our abilities) the limit of our knowledge but not the limitlessness of our caring.

By now I hope that some of you are persuaded that the new medicine is carbon based supported by silicon, in its proper place. As a group, we need to think about investing as much in learning about the people who come to us to find relief from pain, suffering, and illness as we do in making machines and producing techniques that can manipulate data. So learn both to listen to and talk with your patients. Make their concerns your concerns. And most importantly, keep an open mind and heart, and have the courage and fortitude to think about the individual patient. We have been entrusted to ‘care for and care about’ people—and like Sylvan Stool, only a creative mind, a big heart and a good soul can do that well.”

Thank you.