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Patient-Centric Care

Welcome to SETMA's Medical Home "Story Book." The contents are the thoughts, ideas and analysis of SETMA about Medical Home and particularly about our medical home.. Formally, our story began February 17, 2009 when we attend a lecture about Patient-Centered Medical Home (PC-MH). In reality, our medical-home pilgrimage began decades ago. The initial part of our story is organized into three sections, each of which represents articles written in the years 2009, 2010 and 2011. A primer to SETMA's medical home is at: *The SETMA Model of Care: Patient Centered Medical Home; Healthcare Innovation, the Future of Healthcare*.

The following are links to some of our "stories:"

- Paternalism or Partnership - the Dynamic of the PC-MH
- Learning From One's Mistakes
- Medical Home Poster Child
- Patient Centered Medical Home Poster Child: An Update after Five Years of Treatment in a Medical Home
- Evolution of Health Care
- Homicidal Threat to Reciprocal Caring
- Medical Home Pilgrimage - Stories

Never sell your "stories" short; they are the lessons and "learning" of your life. Through them, you will learn and grow.

Perhaps the most creative initiative in the transformation of health care is the concept of PC-MH. At a time when there is great pressure for "reforming of the healthcare system," few understand that it is only transformation which will ultimately make a permanent difference. Reform is brought about by external pressure from without to force conformity to someone else's idea of what healthcare ought to be. Reform only works for as long as pressure is applied and it is often resisted. Transformation is driven by an internalized passion which is generated by principles, convictions and personal vision.

In 2010, SETMA was recognized by the National Committee for Quality Assurance (NCQA) as a Tier 3, Patient-Centered Medical Home and was also accredited by the Accreditation Association for Ambulatory Health Care (AAAHC) and as a Medical Home. In 2011, SETMA

was reaccredited by AAACH for both for a three-year term. In 2013 SETMA renewed NCQA's Tier III Medical Home for 2013-2016. In 2014, SETMA was recognized by URAC and the Joint Commission for ambulatory care and for PC-MH.

It is our hope that this material may stimulate others to start their own Medical-Home pilgrimage and that others will begin to collect their own Medical-Home stories. If so, then this notebook's purpose will have been fulfilled. These articles chronicle our development of a medical home. The developmental history of SETMA will show that as early as 1999, we began defining the principles of what would become SEMTA's Patient-Centered Medical Home. After becoming a Medical Home, SETMA realized that without knowing it, we had spent over ten years developing the functionalities which enabled us to be a medical home.

Our caution to others comes from our own failure which was that initially we focused almost totally on the structures of medical home without understanding the dynamic and spirit of patient-centeredness. Our story will repeatedly illustrate and example the tension between the structure and dynamic of PC-MH.

- Medical Home Series Two: Part I The Movie -- *People Will Talk* (1951)

  People Will Talk is the story of a physician who is opposed by a colleague. Each has a different vision of healthcare. Released in 1951, *People Will Talk* portrays a physician who sees people as more than a disease and medicine as more than a science. The movie is a comedy, a musical, a drama and a suspense story all rolled into one. There are elements of the characters' lives which are not consistent with modern medicine. The main characters smoke, but this reminds us that the tobacco industry used movies and television as vehicles of addiction. The doctor's bride-to-be shoots herself, aiming for her heart, misses and without complication walks out of the hospital the same day as surgery. Of course that is not possible. A cadaver in the anatomy lecture hall has pink skin, make-up and well-coiffed hair. But, in spite of these contradictions and absurdities, there is much to learn from this picture about patient-centered medical home.

  The movie begins with a printed narrative which prepares you for the story. My favorite movies start this way, and along with narration and theme music, movies establish a great pattern for live. The narrative states:

  > "This will be part of the story of Noah Praetorius M.D. That is not his real name. Of course...There may be some who will claim to have identified Dr. Praetorius. At once, there may be some who will reject the possibility that such a doctor lives, or could have lived. And, there may be some who will hope that if he hasn't, or doesn't, he most certainly should.
  >
  > "Our story is also -- always with high regard -- about Medicine and the Medical Profession. Respectfully, therefore, with humble gratitude, this film is dedicated to one who has inspired man's unending battle against Death, and without whom

> that battle is never won. The patient."

Immediately, you know that this story is going to focus on "the patient," and that is also the focus of medical home. The following vignettes from the movie expand on the idea of the patient being the central focus and the most important person in medicine.

The movie opens with Dr. Praetorius waiting for his opponent to arrive in the medical school's anatomy lecture hall. As the medical students sit waiting, Praetorius says, "I cannot give you the lecture which you came to hear and I am not sure that you should hear the lecture which I am prepared to give." With the students' encouragement, he begins, saying,

> "Anatomy is more or less the study of the human body. The human body is not necessarily the human being. Here lies a cadaver. The fact that she was, not long ago, a living, warm, lovely young girl is of little consequence in this classroom. You will not be required to dissect and examine the love that was in her, or the hate. All the hope, despair, memories and desires that motivated every moment of her existence. They ceased to exist when she ceased to exist. Instead, for weeks and months to come, you will dissect, examine and identify her organs, bones, muscles, tissues and so on, one by one. And these you will faithfully record in your notebooks, and when the notebooks are filled, you will know all about this cadaver that the medical profession requires you to know."

Patients are not a disease and they are not a condition; they are human beings and if we are to conduct a medical home, we must see them as more than a patient; we must see them as persons with hopes and fears, loves and hates, beliefs and passions. This is clearly the first principle of patient-centered medical home. It is an effort for a new generation of healthcare providers to capture an old attitude about those whose health needs attention, either because they want to retain it before it is lost, or they want to regain it after it has been lost. It is a frame-of-mind which sees patients personally rather than professionally.

The next medical home portrayal in *People Will Talk* follows a symphony rehearsal. Praetorius is the conductor of the medical students' symphony and after the evening rehearsal, he returns to his clinic to check on a patient. A science professor, a member of the symphony, has dinner with Praetorius and asked if there was anything interesting at the clinic. Dr. Praetorius declares, "A physician respects the confidentiality of his patients and does not discuss them with anyone." In the medical home, all care givers respect the confidentiality of patient information." One of the foundation stones of trust is confidence that personal information will not become public. That which you are certain will be held in absolute confidence can be shared with another.

Continuing with some generic details of a case, Praetorius speaks of his need to involve the family in the solution to one patient's health problem. This extends beyond science and the idea of "patient" and involves the person as a whole being. Realizing how intimate Dr. Praetorius is becoming in this case, his scientist friend responded, "Has it

ever occurred to you that none of this is your business." Praetorius asks, "What is my business?" The scientist declares, "To diagnose the physical ailment of a patient and to cure them." The doctor rejoins, "Wrong; my business is to make sick people well. There is a vast difference between curing an ailment and making sick people well."

This is where "process" - the steps and actions taken in order to "make sick people well" - and "outcomes," which are defined by what "being well" is understood to mean, come together. "Making sick people well," is not defined by avoiding death but by helping people be a whole person - a well person - even while they face death. Repeatedly in the movie portrayal of the life of Dr. Patch Adams, this message is addressed.

Medical Home always involves addressing end-of-life issues, helping persons deal with their own mortality without them seeing death as a failure of life. Death is inevitable; how it is approached determines whether a sick person, who is incurable, can be made well even when dying.

In the second day of the movie's story, a number of medical home concepts are illustrated. As Dr. Praetorius arrives at his clinic, people are outside the clinic building laying in the sun and enjoying the fresh air. Medical home involves normal behavior, even while seeking health care. The first object of medical home is encouraging a patient to maintain wellness. In healthcare, we often place the person, as a patient, in an unhealthy environment. We put them at bed rest rather than keeping them mobile. We limit their food rather than maintaining their nourishment. Often, we them as "being" sick, rather than treating them as healthy people who have an illness. The difference can be the difference between getting well and not.

Realizing that nutrition is central to good health and to "getting well," Dr. Praetorius responses to a nurse who said, "I'd like all the patients to be served breakfast at the same time. I cannot operate the kitchen without more personnel if they are not," saying, "Then hire more people to work in the kitchen." The nurse persists, "But it is common practice in hospitals to serve all the patients at one time." Praetorius declares, "Not in my clinic. No patient will be awakened from a health-giving sleep and forced to eat breakfast at a time which pleases culinary union." The nurse rejoins, "But is it a good economy." Our doctor concludes the discussion by stating, "Bad therapy is never good economy. If you have to economize, do it in the doctors' dining room."

Medical Home puts the patient first and designs processes for meeting the patient's needs and not the staff's. 1951 was a simpler time, but in the 21st Century, it is possible to regain some of that simplicity for the patient's safe. If one patient will eat at 10 rather than at 8 AM; medical home feeds him/her at 10. If another person will eat at any time, he/she can be fed at the staff's convenience. There are great demands upon the time, energy and attention of nurses. There are great financial pressures on healthcare providers and organizations. But, in the face of these demands and pressures, we can remember that in order to "survive" their hospitalization, the patient should, "eat up," "get up" and "get out." The three elements of successful care in the hospital involve

nutrition, activity and transition to home.

While on the subject, Dr. Praetorius turns to another nurse and says, "And I will not have all of the patients bathed at the stroke of a gong for the convenience of the nurses. One of the reasons I started this clinic is the firm convictions that patients are sick people and not inmates." The principle is the same. A bath is a task for a nurse, but to the patient - to the person of their charge - it is an important part of who they are and it has medicinal benefits.

The last scene we will review shows Dr. Praetorius entering a patient ward after the above conversations. He approaches the bed of a very sick patient who is dying, and said:

> "I bet I know what you are thinking, here comes Dr. Happiness; the good humor man. He tries to cheer me up and all I want to do is to hit him with an ice bag. Right?" The patient responds, "Wrong." Dr. Praetorius continues, "Not that I blame you. One of the few pleasures of being sick is the right to be miserable. And, don't let any doctor tell you differently."

The patient said, "I was thinking it's not much fun getting old." And the doctor continues, "It's even less fun not getting old." She answers, "I want to die." Dr. Praetorius says, "You'd like that wouldn't you; just to lie around in a coffin all day with nothing to do."

The patient asks, "Doctor, does it hurt when you die?" He answers, "Not a bit. Where did you get that idea?" The patient states, "They tell me there is so much pain." The doctor, asks, "Did anyone who actually died tell you that?" The patient laughed and said, "Of course not."

Dr. Praetorius then tells the patient about a personal experience he had as a child. He was sick and everyone thought he was going to die. He relates that he felt that he was floating on a cloud and looking down at a scene in a play. He said, "Dying was very pleasant, but when I got better, I had a severe headache and vomiting for three days. I never felt as good alive as I did while I was dying." This scene concluded with the dying lady smiling and saying, "You certainly make dying should like a pleasure, Doctor."

- Medical Home Series Two: Part II The Caution Lights

Have you ever been driving down the highway and suddenly you see a police car? What is your response? I always slow down, even if I am driving the speed limit and I would bet that you do too.. Nothing causes traffic to bunch up like a State Trooper driving the speed limit on an interstate highway. Recently, there is a new "caution" about how fast we drive, which is really effective. You're driving down a city street and suddenly you see a blinking sign which is displaying your speed. I dare you to say that you don't instantly take your foot off the gas pedal and/or put your foot on the brake.

This last happened to me recently. I confess, I took my foot off the pedal. I think it is sneaky but it is equally effective. When this happened to me recently, I thought, "What if we could have signs along the way in our life that flash a warning about the unhealthy decisions we are making?" Do any of you remember the Burma shave signs along the highway? With one or two words per sign, in a series of five or six signs, the message was given. What if those kinds of signs reflected your health facts?

As health care providers increase their use of electronic devices to monitor and measure healthcare status, what if you had a device which preceded you in the cafeteria line? When you picked up a dish which might have an adverse effect upon your health, your "personal health monitor" would flash your most recent cholesterol level with an alert, "caution this dish will make your cholesterol go up." That same monitor would keep a record of the number of steps you have taken during the day and when you sit down in front of the television, that number would flash on your monitor with a red alert, "All illnesses are caused by, or aggravated by a sedentary life style."

Fortunately or not, no such monitors exist and try as I might, I can't imagine how to design one. Of course, Dick Tracy could create one and probably in our future such devices will be available. But how is this related to Medical Home? Again, for better or for worse, home is where we learned our values. We learned concepts of right and wrong, good and bad, and it is in the home where most of us learned the values which would guide us for all of our lives.

So, it is with the Medical Home that we should learn our health values and it is in the Medical Home where our "mental monitor" of our choices should be created. Each of us has the "right" to make bad health choices, many of which choices, we learned in our homes. But, before our health is damaged and while we are still in the position of "retaining our health," the first job of Medical Home is to teach healthy choices and to encourage us to make such choices. Like any value system, our "health choices" education is a collection of "dos" and "don'ts." And, all of these choices can be expressed positively or negatively.

The foundation of Medical Home is health and the foundation of health is nutrition and activity. If we are to have a monitor which mentors us in health, it might be enough to have a small transistor (now that's old technology) which simply whispers in our ear - eat right, keep moving, get up, get out, think, read, be involved in the lives of others.

- Citadel - A 1937 Introduction to the Spirit of Patient-Centered Medical Home

  There is nothing new under the sun, we are told; and, new models of healthcare reinforce the truth of that statement. As we discussed in 2011, the concept of medical home was demonstrated in the 1951 movie, *People Will Talk (see* http://www.jameslhollymd.com/your-life-your-health/medical-home-series-

two-part-i- the-movie). And now, we come to an older movie which addresses the issue of professionalism and entrepreneurism. In the 1937 movie, *Citadel*, we see concierge and subscription models of care illustrated as a doctor abandons his passion for medicine for a commitment to wealth. One summary describes the doctor as being "seduced by the thought of easy money from wealthy clients, rather than the principles he started out with. (He) becomes involved with pampered private patients and fashionable surgeons."

The doctor's pilgrimage has three stages. The first occurs when he miraculously saves the life of a new-born baby. Leaving the family home with a live and healthy mother and baby, he exclaims to himself, "Thank God that I am a doctor." He labors to help the poor and to do clinical research to improve the care of those he treats. His wife is content and happy even though his wages are meager. They live and prosper on their passion not upon their possessions.

After moving to the city, the young doctor is influence by affluent physicians who refer him patients who pay handsomely for unneeded attention from a medical doctor. At first he is shocked at the amount of money which can be made in this turnstile referral system which maximizes reimbursement. Then he enjoys the clothes, the home, the cars and all the other things he can buy. But, his wife laments his loss of passion for medicine even though she has many "things."

Rich, our young doctor is now insensitive to innovative efforts to improve healthcare, brought to him by his friend, many of which innovative opportunities would require him to contribute his own funds to the new efforts. His friend's vision was rejected. Ultimately, the friend was injured in an accident caused by our young doctor's callousness. His friend dies because, while the elegantly dressed specialist has made him wealthy, he incompetently causes the death of the friend at surgery. It is then that our doctor looks around him and sees the suffering and the need and his heart is soften and he returns to his roots.

The Moral Test

At the heart of patient-centered medical home is The Moral Test of a government; Hubert H. Humphrey said: "The moral test of government is how that government treats those who are in the dawn of life, the children; those who are in the twilight of life, the elderly; and those who are in the shadows of life, the sick, the needy and the handicapped." This same test can be applied to healthcare organizations and to health care providers.

In SETMA's September, 2013 Provider training, we watched small parts of *Citadel* and each SETMA provider was given a copy of the DVD. The snippet from the first stage of the doctor's career shows him thanking God that he a physician; the second shows his declaration that he has the right to make money; the last shows recovery of his professional soul as he begins to see the suffering around him. As they played in our

meeting, there was a hush over the room. The gripping heartache, as our young physician sees the suffering around him and as he realizes that he in part was responsible for the death of his friend, caused us all to be silent.

Patient-centered medical home does have a structure and the final steps to being a medical home includes effective structure, the heart and soul of PC-MH is a dynamic born of a passion and a commitment to caring for others and particularly for those who cannot afford the care they need.

- Paternalism or Partnership: The Dynamic of the Patient-Centered Transformation

The dynamic of the medical home redefines the relationship of healthcare provider and patient, and changes how they relate! Rather than the patient encounter being **didactic** (to lecture or teach, as one with knowledge instructions or informs those who do not) - where the healthcare provider tells the patient what to do, how to do it and when to do it - the patient/provider encounter becomes a **dialogue (**An exchange of ideas or opinions) - where the healthcare provider and the patient discuss a mutual concern and then together come to a mutual conclusion with a mutually agreed upon plan. This new relationship is somewhat like a partnership.

Healthcare Providers No Longer Constables

The concept of a patient encounter being a dialogue where the interests and desires of both parties are respected and engaged is alien to the old paternalistic model of care. The only way in which the patient-centric conversation in a healthcare encounter can be a dialogue is where patient and provider become collegial and where they entered into a collaborative relationship.

On October 1, 1999, five months after SETMA had defined the structure of the medical home, SETMA published a booklet about EMR entitled, *More Than a Transcription Service: Revolutionizing the Practice of Medicine And Meeting the Challenge of Managed Care With Electronic Medical Records (EMR) which Evolves into Electronic Patient Management* (the booklet can be read athttp://www.jameslhollymd.com/your-life-your- health/transcription-more-than-a-transcription-service). In that booklet, SETMA said:

> "Doctors need to learn new technological ways of organizing and conducting the business of medicine. They need to allow the power of information systems to change the way they approach healthcare. They need to maintain personal contact; patients are people first and last, but doctors need to see EMR as a powerful tool and not simply as a new and expensive toy. If they do, they will begin the 21st Century with an ability to impact the delivery of healthcare in America.

> "Healthcare providers must never lose sight of the fact that they are providing care for people who are unique individuals. These individuals deserve our respect and our best. Healthcare providers must also know that the model of healthcare delivery, where the provider was the constable attempting to impose health upon an unwilling subject, has changed. Healthcare providers progressively are becoming counselors to their patients, empowering the patient to achieve the health the patient has determined to have. This is the healthcare model for the 21st Century and the computerized patient record is the tool, which makes that model possible."

In 1999, we did not know that we were defining the most critical half of patient-centered medical home, i.e., patient-provider collaboration. It would take thirteen more years before terms like "shared decision making," "activated patients," "patient engagement," "patient-centered conversations," and programs like "Conversation Ready" would guide us to the fulfillment of the vision of patient-centered medical home. In coming weeks, we will look at illustrations of the fulfillment of the dynamic of patient-centered care and at illustrates of how we failed to practice that dynamic.

- What is patient-centered communication? Have you really addressed your patient's concerns?

  This link is to a power point presentation which was prepared for one of SETMA's monthly training meetings. This study is based upon a paper entitled, "What is Patient Centric Conversation," (*FAMILY PRACTICE MANAGEMENT(*www.aafp.org/fpm), March 2008, Ronald M. Epstein, MD, Larry Mauksch, MEd, Jennifer Carroll, MD, MPH, and Carlos Roberto JaÃ©n, MD, PhD." The paper includes concepts such as: "A physician-dominated medical encounter, with little opportunity for patient input," "A patient-centered medical encounter, without explicit agenda setting," "Two important elements of patient-centered communication: drawing out a patient's true concerns and identifying which ones to address first." "Physicians often assume that: first concern a patient mentions is the most important one; that patients will spontaneously report all of their fears and concerns." Neither of these assumptions is true. Think of the patients who wait until the end of the visit to report substernal chest pain.

  It was only after reading, studying and teaching the concepts in this paper that I truly understood what a patient-centered conversation was.

- SETMA 8.20.13 Provider Training -- Health Affairs 2.14.13 -- Patient Engagement

  This power point was created from the *Health Affairs*, February 14, 2013, and was taught in SETMA's Provider Training, August 20, 2013. It contain concepts of patient engagement such as: "A growing body of evidence demonstrates that patients who are more actively involved in their health care experience better health outcomes and incur lower costs"; "'Patient activation' refers to a patient's knowledge, skills, ability, and willingness to manage his or her own health and care"; "'Patient engagement' is a

broader concept that combines patient activation with interventions designed to increase activation and promote positive patient behavior, such as obtaining preventive care or exercising regularly"; "'Patient engagement' is one strategy to achieve the 'triple aim' of improved health outcomes, better patient care, and lower costs."

- Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS): Tutorial for SETMA's Internal HCAHPS Survey

  Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) is a structured set of standards by which to measure healthcare provider and hospital performance. SETMA has long had the philosophy that if healthcare providers are going to be held accountable for certain actions, they ought to: Know what they are going to be held accountable for; Measure their performance before an external organization reports this performance at some distant time in the future; Have a plan and a method for improving their performance. In August, 2014, SETMA designed a system by which SETMA's Care Coordination department in the Care Coaching Call the day following discharge from the hospital, SETMA could assess our own HCAHPS performance. While this will not be accepted as THE official score, it does involve SETMA providers in the fulfillment of these standards. Below this tutorial is a lengthy discussion of SETMA's 8-day pilgrimage to excellence in HCAHPS performance as a function of patient-centeredness in inpatient care. This is the beginning of our becoming patient-centered in our inpatient care...

- The Conversation Project

  For patients, traditionally, healthcare has been a spectator sport. Almost like a passive bystander, patients were told what, when, where and how to receive "healthcare." That system worked fairly well when there was little which could be done for illness; but, in the 21st century when many things can be done, new questions arise such as:

  1. Even when something can be done, should it be done?
  2. When there are several different things which can be done, which one does the patient want done?

  Maureen Bisognano, CEO of the Institute for Healthcare Improvement (IHJI) and a recognized international expert on improving healthcare systems, has taught us to ask a much more profound question and that is, "What do you want?" The elimination of the word "done," changes the healthcare conversation from one of procedures, tests, services, etc., to one of outcomes, goals and desires. It changes the conversation from science to humanity.

  One of Maureen's most significant contributions to healthcare improvement -- The Conversation Project -- resulted from her personal experience. The Project; is IHI's program to make certain that healthcare providers, healthcare recipients and the healthcare system know how to talk about end-of-life issues. The key is to ask the question, "What do you want?"

Maureen's personal and poignant story was about her brother who died when he was 21 and Maureen was 23. She shared their story:

"When my brother Johnny was 17 years old, he was diagnosed with Hodgkin's disease. It progressed quickly, and he was in and out of hospitals regularly over the next several years. When Johnny was 20, he came to my apartment and told me, 'I'm not gonna make it.' He was ready to face death, but I wasn't. I didn't know what to say or do. All I could think of was to offer encouragement and try to give him hope. But Johnny stopped me and asked me, 'Can I tell you what I want?' 'What do you want? I asked him. 'I want to turn 21,' he said.

"Johnny did turn 21 and died just a few days after that birthday. Throughout that last year of his life, I still didn't grasp the power of that simple question that Johnny was asking me to ask: "'What do you want?' Looking back, I wonder what might have come from asking that question. I wonder about the people Johnny would've wanted to meet and see. I wonder about the conversations they might have had. And I wonder about the functionality he could have had, to the extent he could, out of the hospital. But instead of Johnny realizing his wishes for his last year, he spent it mostly in the hospital. I finally learned the power of the question from a radiation oncologist. While Johnny was in the hospital during that last year of his life, doctors would come and go from his room. They'd speak over him, and about him, but almost never to him. Finally, this radiation oncologist went into my brother's room and asked him, 'Johnny, what do you want?' 'I want to go home,' Johnny answered.

"The doctor then took off my jacket, put it on Johnny, picked him up from his hospital bed, and carried him to my car. Johnny came home, and spent his final days surrounded by the friends and family that loved him. That one interaction between Johnny and the radiation oncologist taught me not to rely on just providing encouragement and hope. These things are important, but more important, almost always, is having the conversation with a loved one about what they want. Find out what they want, then act on it, and carry it through. Trust me, you'll be forever grateful you asked, 'What do you want?'" I wept as I read this story for the first time.

Patient-Centered Medical Home (PC-MH)

As Southeast Texas Medical Associates has spent the last five years becoming a PC-MH, we have developed technologies to do "things" and to perform "actions" and to fulfill "metrics," but we have only recently begun to understand the power of "patient centric conversations," "patient activation," patient engagement," and "shared decision making." We have begun to understand that each of these categories is more than a once-and-for-all act. They are a dynamic which are more accurately addressed in the continuing tense of the verb. We have begun to understand that patient-centric requires continuous re-engagement more than just engagement, continuous re-activation more than just activation, and patient-centric conversions are not a single conversation but is an on-going dialogue which takes place at many venues, at many times and with many

different contents. We have begun to understand that patient-centric is more completely defined by the profound question, “What do you want?” than it is by the powerful electronic capabilities we have created.

IHI’s ‘the Conversation Project”

SETMA’s end-of-life conversation, which we perform with every patient and which we document as part of the structure of our medical home, is always begun by “What do you want us to do?” What we should be asking is, “What do you want?” My life stories reinforce what Maureen has taught us.

As a sophomore in high school, I learned a lesson which has enabled me to carry out the most difficult personal and professional tasks. One day, my friend’s father died suddenly. That evening, I went his home. I remember feeling very awkward. I knew that I should be there, but at fifteen, I didn’t have the foggiest idea what to do, or what to say.

Only one other friend came. We made small talk and tried to forget the great loss. At one point, we were talking about our families. I said, “If my father ever did that, I’d kill him.” If spoken words have a life beyond the hearing and memory of those present, these words seemed to have; eternal life. They hung in the air like a Damocles sword waiting to fall on my head. If I did not know what to say, I surely knew what not to say and I had just said it. Kindly, my friend glossed over my blunder. The evening ended with goodbyes and expressions of sorrow.

The next day, after his father’s memorial service, my friend was sitting in the family car. I walked over and said, “Louis, I don’t know what to say.” Wiser than I at fifteen, he said, “You don’t have to say anything, you were there.” To that point in my life, I had never heard kinder words. They echoed in my mind louder than what I had blurted out the night before. I turned them over and over in my mind, again and again. My friend and I never spoke about this, but fifty-five years later, I have never forgotten those words.

Twenty years ago, I had a 24-year-old patient who declared that she had a dread disease but no diagnosis could be made. A year later, during a pregnancy, we found the malignancy which was incurable. She was from the Pacific Northwest and returned there. Three months later, she called me and said, “Can I come home?” As she was with her parents, I thought she was. She added, “No one will talk to me; they pretend that everything is OK,” They had the same problem I had when I was fifteen. She concluded, “I want to come home so that I can talk about what is happening to me.”

She returned to Southeast Texas and for the next six months, we visited and talked often. We prayed and planned for her son’s life. My wife and family were involved with her. Never once did we talk about medicine, surgery, pills or treatment. She did not want that; she wanted to come home. She wanted to talk about the future and her

life, not her death. We never talked about healthcare; we talked about what she wanted.

- Patient and Family Engagement: Part I

  Addressing the importance of patient engagement the authors quoted other sources: "'Patient engagement has been called a critical part of a continuously learning health system', 'a necessary condition for the redesign of the health care system', the 'holy grail' of health care, and the next 'blockbuster drug of the century'." The concept of a "continuously learning health system" is not developed in this article, but it is illustrated. As stated by Peter Senge in The Fifth Discipline, "continuously learning" is not so much defined by the "taking in of more information," but it is the "changing of one's mind" about the structures and systems which leverage change in the processes and outcomes of healthcare delivery. It is this kind of learning we are pursuing in understanding "patient engagement." While giving the healthcare community theories about healthcare delivery redesign, the authors also have given us practical descriptions and guidelines for how to implement patient engagement.

  Definitions

  Definitions and understanding of the concepts of this redesign are inextricably related. The authors stated: "Adding to the confusion, the term patient engagement is also used synonymously with patient activation and patient- and family-centered care. Although the concepts are related, they are not identical" If healthcare providers are going to be able to make the transition from expecting "compliance" on their clients part, to the experience of patients "adhering" to a mutually agreed upon healthcare plans of care, it is imperative that we understand the vocabulary.

  - "Patient activation-an individual's knowledge, skill, and confidence for managing his/her own health and health care -- is one aspect of an individual's capacity to engage in that care. But this term does not address the individual's external context, nor does it focus on behavior.
  - "Patient- and family-centered care is a broader term that conveys a vision for what health care should be: a partnership among practitioners, patients, and their families (when appropriate)' to ensure that decisions respect patients' wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care.
  - "...Patient and family engagement as patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system-direct care, organizational design and governance, and policy making-to improve health and health care. Although we use the term patient engagement for simplicity's sake, we recognize that those who engage and are engaged include patients, families, caregivers, and other consumers and citizens."

  With these definitions, we can begin to design activities which support the processes they identify. The authors then identify circumstances which are driving patient engagement:

- "First, work related to patient- and family-centered care and shared decision making both reflects and accelerates the shifting roles of patients and families in health care as they become more active, informed, and influential.
- "Second, a growing body of evidence suggests that patient engagement can lead to better health outcomes, contribute to improvements in quality and patient safety, and help control health care costs.
- "Third, virtually every discussion about the US health care system begins by noting that spending is spiraling upward while quality lags behind. In the search for solutions, gaining ground is the belief that patients are at the core of our system and, as such, are part of the solution."

Similarities to Healthcare Reform and Healthcare Transformation

In many ways, patient engagement, patient activation, and patient centeredness, which all lead to patient adherence as contrasted with the coercive nature of the concept of compliance, are not unlike the dialectic between healthcare reform and healthcare transformation. Healthcare reform, similar to patient compliance, comes from the external pressure of rules, regulations and requirements. Healthcare transformation, similar to patient adherence comes from internalized ideals which become a personal passion. Ideals voluntarily adopted create a tension between the current state of affairs and the goals of the ideal. That tension creates a transformative energy which is therefore self-sustaining and generative.

Exhaustion in healthcare delivery results from providers trying to "drive" the patient to good health. This is the "old system" where the provider was the "constable" attempting to impose health upon the patient. When the patient is engaged and activated by patient-centric care, the patient joins the provider in driving the healthcare process to excellence. This is the "new system" where the patient and provider are colleagues, working together for common goals and outcomes.