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Continuity, Creativity, Consistency
Part VIII The Power of Story Telling
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In ancient times, the power of story telling was well known. History was communicated by story telling. Values and beliefs were transmitted from generation to generation by story telling. Families sat around fires and tables and told stories. Young people sat at the feet of old people and listened to stories which helped them understand who they were and what was required of them. Sacred texts began as stories told for generations, and they were told precisely and accurately.

First print and then electronic media adopted the pattern of story telling; they called it “news” and “reporting.” Radio, television, computers and cell phones began to take up the story telling time. Often, rather than enhancing our lives, these media diminished that value particularly by incidentally devaluing personal and family stories with dramatic cinema graphic and Technicolor story telling.

However, to realize how well and how alive “story telling” still is, one only has to ride a bus, a train or fly on plane to discover how readily people want to tell their story and how eager they are to do so even to do so to perfect strangers.

Anecdotal medicine – story telling medicine -- is frowned upon as it is based on personal experience without the benefit of "random controlled" or "double-blind" studies. Anecdotal medicine does not allow for analysis to determine if the conclusions of the personal experience are valid or not. Nevertheless, story telling is still an essential part of being human.

In the case of Medical Home, while there is an objective standard against which to measure the essential functions of a Medical Home, it is the "stories" which are powerful. It is the "stories" which give breath (in this case we refer to respiration and life) and depth (in this case we refer to significance and validity) to the healthcare experience.

In fact, SETMA would recommend that NCQA, AAAHC, the Joint Commission and URAC - currently, the four agencies reviewing Medical Home applications -- establish a "stories exchange." This would be a place where illustrates of successes or learning in Medical Home

could be shared with everyone. Each story will flesh out, in three-dimensions "real life situations," our understanding of what otherwise are two-dimensional abstract ideals such as "coordination," "Care Transitions" and "patient-centric conversations," among others.

While we often don't think of it in terms of "story telling," every patient encounter is an exercise in a form of story telling. Often that story is guided by medically related questions but in the context of the Patient-Centered Medical Home the more effective patient interview is found in allowing the patient to "tell their own story, in their own words, in their own way." Not only does that method give a more granular picture of a patient's needs but it increases patient satisfaction greatly. The patient-centered conversation, which is the structure of that story telling was discussed in part seven of this series.

Perhaps no other single activity is more helpful to the PC-MH transformation of a medical practice than is the intentional telling of the practice's own stories. The following are benefits of stories:

1. They give us insight into the progress we are making in our transformation efforts.
2. They capture "lessons learned," mistakes corrected, and processes changed.
3. They give a human face to an often otherwise impersonal activity.
4. They help us remember "from whence we have come" and "whither we are going" (see Abraham Lincoln and Modern Healthcare for the original of that last phrase)
5. They give us an effective and charming way of relating our pilgrimage to others in an interesting and memorable way.
6. They provide a map for others and they teach others how to tell their stories for themselves.
7. They allow us to memorialize and acknowledge the contribution of others and particularly of our collaborators who formerly were called "patients."

Let me give you an example. The full story can be read at: Continuous Professional Development: Learning from a Convergence of Events.

In shared decision making, providers and patients exchange important information. Providers help patients understand medical evidence about the decisions they are facing and patients help providers understand their needs, values, and preferences concerning those decisions. Then, ideally after allowing time for reflection, patients and providers decide together on a care plan consistent with medical science and personalized to each patient.

The story which is my example is related in an abundance of caution, I do not mention the patient's gender, age or ethnicity, or the precise date I saw the patient. For the past seven years, I have used this story to illustrate how we should respond to patents whose needs we have not met, that do not follow our plan of care and our treatment plan. I have told this patient's story many times as an illustration of one of the aspects of the best of patient-centered medical home. Four years ago, I learned by review how far that was from the truth.

I knew the facts of the patient's encounter well but I wanted to review it to make sure I remembered it correctly. Four years ago, it took me a little while to find the original, contemporaneous summary of the patient's post clinic summary of care. When I did find it and

reread it; I was shocked to see that there was an element of the case which I had not remembered and it was THE key element.

Conclusion: Unintentional Neglect of a Patient

As I re-read the patient's record, and after "seeing' what I had not heard (had no "paid attention to") at the visit, I thought and even dreamed about that visit over the following weekend. Over and over and over, the words rang in my head, "I want to lose weight."

I remembered well that once I had completed the patient's history and believed that He/she had undiagnosed diabetes, I settled on treating her/his diabetes and unintentionally ignored the patient's desires. I was certain that the patient had diabetes; which she/he did. And, I was determined to give the patient excellent care; which I didn't. Rather than explaining to the patient why I don't treat weight loss with Ionamin, thyroid and diuretics, I just ignored her/his goal.

Because I ignored the patient's goal; the patient ignored my plan. I saw him/her on a Monday; I called him/her on a Tuesday. I had our Care Coordination team call him/her on Friday. And he/she said, "I enjoyed the visit; I will return, but I am not going to… and listed every element of my plan of care. Four years ago, I and my staff tried to locate the patient without success, I realized that while I would have labeled the patient "non-compliant" using ICD-9, ICD-10 or SNOMED codes for that diagnoses; the real diagnosis should have been "failure to communicate," "non-patient-centric care," "failure to activate the patient," and/or "failure to engage the patient."

The fault was not the patient's; the fault was mine. What if I had engaged the patient in a conversation about weight reduction? What if I had discussed with the patient, the reasons why I don't prescribe Ionamin, thyroid medicine and diuretics for weight reduction? What if I had walked the patient through SETMA's Adult Weight Management program? What if I had said, "While we are helping you lose weight, we can also help you control your diabetes?"

Until that moment four years ago, my memory of this patient's care was that of excellence and of the sad rejection of that care by the patient. Today, I remember this patient's care as my failure due to the hubris of "my thinking that I knew better." If my goal had been to help this patient and it was and is, then I should have met the patient's needs and expectations in order to gain the opportunity to meet the patient's real health needs. As it turns out, I have the opportunity to do neither.

The recognition of having made a mistake

Plutarch said, "To make no mistakes is not in the power of man; but from their errors and mistakes the wise and good learn wisdom for the future." My mistake can be forgiven if I learn from it. And, how will I evince that learning?

I think I shall never see a patient without asking the question, "What is your goal?" "What do you want to achieve in this visit and in the care you will receive from this clinic?" That question

is partially answered when the patient-encounter record documents the patient's "chief complaint."

But to make it more explicit, we are today adding a comment box to each disease management suite of templates and to each suite of templates. It will be labeled: "Patient Goal." It will be expressed in the patient's words." While we want to use structured data fields, this may be one case where structured data fields obscure the issue. As we have more experience with shared-decision making, we will clarify this data field more precisely.

But, we will never ignore a patient's personal goal again. And, if the patient's goal is something which is inappropriate, or which can't or shouldn't be done, we will address that directly and frankly, rather than just by ignoring it.

I hope I get to meet this patient again. And, if I don't, I shall see her/him in the face and eyes of every patient I see, as I focus upon their goals and desires in order to have the privilege and opportunity to meet their real health needs.

Our stories are the means for remembering and by remembering we improve. (see: Medical Home - The Story and the Ideals for more "stories and ideals.")