



Patient Home Advantage

Giving families a voice.

11161 Kenwood Road, Cincinnati, OH 45242
(513)744-4633

Patient Engagement: Problem Definition

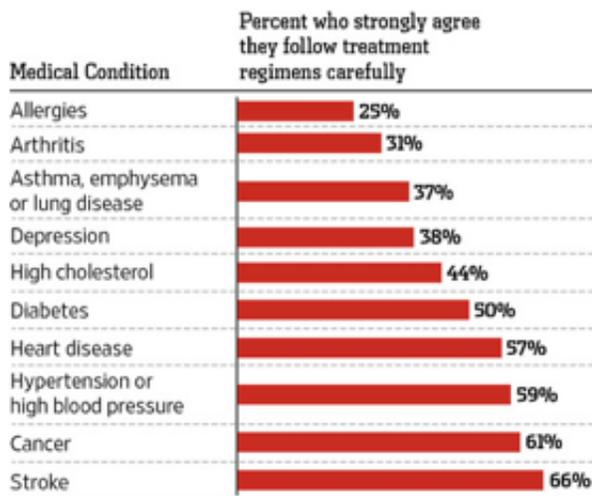
Dr. Gary Sweeten

Children and adults with a chronic illness/disability are best supported in the environment with the people who love them the most. This is usually a family. People do better physically, mentally, emotionally, and spiritually when they are in an environment of family and friends who know them and their needs best.

Second, the disease model has largely excluded patient and family from diagnosis, care, and treatment. The training, payment, and practices of medical personnel focus on Professional Diagnosis and Treatment. There is an increasing emphasis on prevention and wellness with very little success, as the chart below from the Wall Street Journal indicates.

Doctors' Orders Ignored

For certain chronic conditions, adherence to treatment recommendations is spotty, according to a survey of privately insured adults age 21 to 64



Patients on the Sidelines

How one analysis categorized Americans based on their level of involvement in managing their own care



Source: Employee Benefit Research Institute, 2008; Center for Studying Health System Change, 2008; Judith H. Hibbard and Peter J. Cunningham

The Wall Street Journal

In addition to these data, it is reported by Prochaska that on average only about 50% of patients seeking mental health assistance follow through with the suggested treatment prescriptions. Scott Miller and his colleagues indicate similar results when patients are not encouraged to set their own goals.

Three, the Affordable Care Act and the Individuals with Disability Education Act each emphasizes a radically new treatment. They insist treatment be carried out as closely as possible to the living space of the family rather than in the clinic, school, and hospital. The role of the professional has changed from that of a treatment expert to include motivating patients to do self-care. The only way for professionals to survive economically is to motivate patients to be fully engaged in wellness.

Four, people are most motivated to engage in wellness when they decide why, what, when, and how to be engaged. Many Patients resist being told by others what they should do. When experts insist, people resist.

Research on Empowering Patients for Self-Care

A summary from pages 23-25 of E-patients White Paper, by Dr. Tom Ferguson, M.D. and the e-Patients Scholars Working Group, March 2007. The term *e-patients* means people that are equipped, engaged, empowered, and enabled to participate in their own health care.

There have been several attempts to *empower patients* by giving them targeted medical information that 'prescribed' selected medical content in the same way that they would prescribe medical information about prescription drugs. However, outcomes studies show that the desired 'empowering' did not work as planned. Here is why.

Top down Prescriptions of Medical Information are often harmful rather than helpful. Elizabeth Murray of the Cochrane Collaboration reviewed the medical literature about patients with chronic disease. They were targeted for interventions by professionally-developed interventions via the internet. The targeted patients had an increased knowledge of their condition and an increased perception of social support. A. The prescriptions had no effect on the patient's sense of self-efficacy. B. No positive impact on the patients' health related behaviors. C. They had WORSE OUTCOMES THAN THOSE NOT TARGETED!

Similar outcomes have been found in other professionally developed educational programs intended to empower patients like telemedicine, information therapy, patient handouts, etc. The key to success is not content, but the relationship between the medical professionals and the patients. If the relationships continue with the professionals on a pedestal and the patients as poor, ignorant, dependent and unable to understand their illness, the medical content will harm the patients self-motivation.

Kate Lorig and her colleagues at Stanford agree <http://patienteducation.stanford.edu> Her studies began in the early 80's and also concluded that **content does not matter much!** Many of the IT programs designed to empower patients had the opposite effect. One group developed a computerized education system for migraine patients. The developers of the program made four assumptions about the patients.

- That they know nothing about migraines; b. that they needed to know only what the clinician wanted to tell them; c. the only reason clinicians do not present the proper information to the patients is a lack of time; d. that the patients had much to learn

from the Neurologists but they had nothing to learn from the patients. All four assumptions were wrong:

- Many of the patients had read extensively. They knew things about the disease that physicians did not know. They had experiences as to what happens during a migraine and the best ways to manage it. What the patients want to know is radically different from what they were given.
- Patients have knowledge and experience useful to others but were ignored by clinicians.
- Clinicians regularly dismissed non-medical questions and ignored patients' concerns.
- The clinicians did not listen to the patients. They dominated the interactions so the patient had little time to ask questions.

The version did not allow the patients to: 1. Discuss issues not on the clinicians list. 2. Use their own words, but had to use the clinician's words. 3. Give the doctors feedback. 4. Tell doctors about new research. The system did not address power, knowledge, relationships, traditions, and old habit patterns. "They built a very powerful IT System that had the same profound cultural, traditional defects that patients had always faced in the clinic." **There was no empowering of patients.**

Conclusion: "Most medicine is ten parts culture and one part real science. From a medical anthropologist's point of view, a great deal of what goes on is invisible to most clinicians". What matters most is helping the patients believe they CAN MANAGE their own health. They communicated this with certain messages:

- a. You can run the show; b. positive encouragement; c. training and retraining and rehearsing skills; d. modeling ways to carry your own, self-devised action steps that bring better health such as a diet, exercise, etc.

The key to effectively communicating helpful information is to interact with Genuineness, Respect, Empathy and Warmth (GREW) and do it in a humble, interactive, collaborative manner. Listening by the clinicians is crucial to fostering self-care and good health. Summary by Dr. Gary Sweeten for Patient Home Advantage, L3C® and Sweeten Life Systems, www.Sweetenlife.com

Other research noted by Stephen Wilkins at Adopt One Challenge shows why patients and their family members are usually left out of the process. 1. In only 26% of doctor visits were patients allowed to finish their first statement about the reason for the visit. In 37% of the cases the patients were interrupted before they could finish. 2. In 75% of the cases, doctors failed to ask what was wrong. 3. When a medicine or action was prescribed, the doctor spent 60 seconds or less explaining what it was for and how to do it. 4. Over 50% of the time patients disagree with their diagnosis. 5. Over 50% of the time the patient leaves without knowing what to do or why to do it. 6. The patient's insights and action steps are solicited 18% of the time and is asked to engage in mutual problem solving only 34% of the time. As a

result, many patients fail to comply with prescriptions and have medical crises that require expensive treatment.

Unfortunately, insurance companies are using the same highhanded methods to try to force workers at businesses to start programs of self-care. They pay membership in health clubs, do in-depth surveys of members' eating and exercise habits, and try to force unsubstantiated ideas about health and wellness on the companies by increasing premiums if the people fail to comply. It will backfire! The data show a lack of compliance and better health practices when workers are not encouraged to select their own activities. The Family Resource Builder actively engages workers and family members in deciding priorities and goals.

“The more experts insist, the more patients resist!”®

www.patienthomeadvantage.com

Always treat others the way you want to be treated. *Jesus*