

National Summit on Medical Errors and Patient Safety Research

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Personal Testimony of Marie Savard, M.D.

“Each patient carries his own doctor inside him. They come to us not knowing that truth. We are at our best when we give the doctor who resides within each patient a chance to go to work.” *Albert Schweitzer, M.D.*

I have been witness to the challenges of our health care system for the past thirty years, first as a nurse and then as a primary care physician. I worked in both a solo and group practice, was medical director of Quality Management at Pennsylvania Hospital in Philadelphia, testified as a medical expert in a number of malpractice cases, and was advocate or “health buddy” for my once seriously ill husband and my father. Although never critically ill, I also have three teenage sons who have experienced the usual array of illnesses and contact with the health care system.

During those three decades, the health care system has become increasingly complex and fragmented. The long-standing paradigm of the all-knowing physician as the authority figure in a white coat doesn’t work anymore. A number of exciting developments have set these changes in motion. Medical research has yielded breakthrough after breakthrough in diagnostic techniques and treatment options giving many of us a chance to live longer and better. However the corollary is that while yesterday’s physician knew just about all there was to know back in his time, no doctor today can keep up with every single one of the near-miracle advances that are being made

almost every day. A growing number of specialists have helped, but still, no one doctor can possibly keep track of everything.

The downside of today's environment is that the advent of managed care has meant that doctors typically have a "panel" of 1,000 patients or more, many of them new, and lots more paper work. In contrast, yesterday's physician had fewer patients and cared for them from cradle to grave. He knew their names, he made house calls, and kept all their medical records on an index card tucked away in his desk drawer. Today's doctor can't possibly keep all of that in mind. I remember once being so swamped and rushed that I found myself wishing that I had a snapshot of each patient stapled to the front of the chart to help me recall who I was to see next. Add to this the fact that people move around a lot these days – kids go away to college, employees get transferred or change health insurance and retirees travel to the Sunbelt.

During my thirty years of practice in health care, I have witnessed hundreds of mistakes arising from the complex circumstances of modern medicine. Some of these "pitfalls" and potential solutions to them have been described in the Institute of Medicine's report titled "To Err Is Human". Many of the solutions require significant research, public disclosure and top-down support and implementation. All of this will take considerable time and untold resources while avoidable mishaps continue to cause injury and death.

It is my belief that people (patients) today have the power and means to protect themselves and get the best health care possible. It is a matter of teaching and encouraging people (patients) how to manage and control their own health care, something no doctor or computer program can do for them. To paraphrase the words of

Albert Schweitzer, M.D., we are at our best as clinicians when we put the doctor inside of each patient to work.

Research has already shown, and my own experience has confirmed, that the more involved and informed each patient is in preventing and managing their conditions, the better their health outcome. In the words of Kaplan and Greenberg from their often quoted Medical Outcomes Study, “No amount of technically excellent care will produce optimal outcomes if patients are not actively engaged in managing disease, particularly chronic disease.” (1)

Although research has demonstrated the importance of greater patient involvement in their care, much less attention has been paid to helping the physician and patient achieve this goal. Doctors vary widely in how much they facilitate a patient’s active participation although again, research has shown that participatory decision-making style is a valid and reliable indicator of the quality of patient care (2).

Non-adherence and confusion about prescribed medical regimens contribute significantly to the problem of medical errors, not to mention the adverse clinical and economic consequences. Prescription under-use is 40% or more for patients with diabetes, hypertension, arthritis, or patients on hormone replacement and 20 to 30% for patients with asthma or in need of anticoagulation (3). Common reasons for this under-use include concerns about side effects, efficacy, and cost (4). The major factors influencing adherence once prescriptions are filled are the patient’s perception of the seriousness of the condition and of the efficacy of treatment, the chronicity of the condition and of treatment, and the quality of the doctor-patient relationship (5). Education alone is insufficient to correct the problem. A fully engaged patient is a vital

and necessary part of the solution. This solution of involving the patient more fully does not require a significant outlay of funds and years of research or need for public disclosure.

In summary, despite a long history of advocacy for increased patient involvement and evidence that patients want more information and participation in their care, too few meaningful attempts have been made to change the traditionally passive role of the patient. Patient safety and patient involvement are necessarily linked. The current national spotlight on medical mistakes and need for improved patient safety provides us with the opportunity and obligation to correct these problems. Central to an involved patient, and therefore one of my proposed solutions to patient safety, is a patient-held medical record.

I propose a nationwide effort to pave the way for a new era where patients are viewed as full participants in their health. My hope is that someday soon patients will routinely archive their own medical records, have confidence in their own instincts, research their conditions, shoulder the responsibility for prevention and adherence and learn to work in a true partnership with their clinicians.

I have developed a system (The Savard System) that can be taught in medical schools, elementary and high schools, within advocacy and community groups, and in the clinician's offices. To that end, I am currently developing a curriculum for each of these audiences. For example, I am working on a curriculum for entering high school students and will pilot it this year at Philadelphia's public school, University City High School. Each student will be provided 1) their own copy of *The Savard Health Record*, a three-ring binder system that teaches people how to collect, store, and understand their medical

records and manage their health care including designing their own preventive health program; 2) the text *How To Save Your Own Life: The Savard System for Managing – and Controlling – Your Health Care*, a book that teaches step by step how a person can manage her own health care and 3) a workbook of sample forms and information. At the completion of the course students will have learned through interactive lectures, role-playing, and clinical shadowing how to collect and understand copies of their medical records, design their own preventive health schedule, manage their health conditions and partner successfully with their doctor (clinician).

The following vital steps of my program are generic to any audience and will include discussion of the safety problems each step addresses and the proposed solution.

I. Learning to trust the doctor within each of us as we are our own best experts on ourselves and our families.

So often patients have an intuitive feeling that something is wrong, but never seek help, are afraid of being considered pushy, paranoid or told the problem may be all in their head. Patients are too humble for their own good and cowed by doctors and other health professionals. They are afraid to have faith in their own instincts. Time and time again when I ask patients what's wrong they have said, "You tell me. You're the doctor." Technology can never substitute for what "you know about how you feel – and how it is different from the way you usually feel."⁽⁶⁾ My job is much harder if patients don't tell me what they think may be wrong and keep me abreast of their symptoms and concerns. I have reviewed hundreds of cases where patients were prematurely discharged from emergency rooms or doctors offices only to be later diagnosed with serious, sometimes life-threatening conditions. When the family member is asked why they

didn't speak up and express their concerns they commonly reply, "I trusted him. He is the doctor."

Research has shown that patients often know more than they think they do about their health. For example, researchers at Purdue University tracked patients and their doctors for many years, asking them to rate their health. In every case, the patient's own report was as accurate or even more accurate than the physician's. In the words of Sir William Osler, "Listen to the patient. He is telling you the diagnosis."

Studies have shown that 80% of what a doctor goes on to make an accurate diagnosis comes from a patient's medical history and records.

Suggestions and Research Opportunities:

- 1) Nationwide educational/publicity effort to emphasize the importance of trusting your own instincts about your health or your family member's health.
- 2) Teaching patients the warning signs that could signal serious and potentially treatable conditions. For example, I list the worst case and best case scenarios for 18 symptoms in my book, *How To Save Your Own Life*.
- 3) Teach patients, medical students and practitioners about the important role of denial, how to recognize it and ways to deal with it. Former President Gerald Ford may have been in denial when he apparently insisted on being discharged from Hahnemann University Hospital during the Republican Convention last month after only a brief emergency room evaluation with symptoms consistent with a stroke or other serious illness. The possibility of denial should have been recognized and addressed.
- 4) Encourage widespread use of a health advocate or "health buddy". Each one of us can be easily intimidated by a doctor or emergency room visit or be in denial about

the potential serious nature of our symptoms or circumstances and forget what was discussed or recommended. A health buddy could help in preparing for the office visit, speak up during the office visit, and help remember the discussion and recommendations made to improve adherence to regimens. This health buddy concept at all intersections of our health care would help address many problems including patient safety issues, non-adherence to suggested regimens, confusion in medication doses and directions, problems with denial, and tendency to believe that no news is good news when it comes to test results.

II. Collecting, reading and storing complete copies of actual medical records (the patient-held medical record)

The information in one's medical record is arguably the most private and important information we have. As already stated above, most of what a professional relies on to make an accurate diagnosis is learned from the medical record and history. The more complete the history and record, the more accurate the diagnosis. Yet the days of a solo doctor having all one's medical information tucked in a manilla folder are long over. Most medical records exist piecemeal in an array of offices, computers, laboratories, and on microfilm at one or more hospitals. When people move (1 in 5 people move on a regular basis) or change insurance (revolving door of managed care suggests patient change frequently) or travel to the Sunbelt for the winters, records rarely follow intact. Records are often not complete or available during office visits because of the many problems of medical record departments and staffing. Important test results and reports are often mis-filed. Computer and hard copy records may contain a number of

errors. Specialists are often asked to evaluate a patient with minimal information, often only a few words hastily scribbled by a referral nurse or office worker (and not always at the direction of the referring physician).

Even if medical records were complete and accurate (and eventually electronic) and available at every office visit, there is an additional reason why patients should have a copy of their own medical record. The work of Kaplan and Greenberg (7) in the now famous Medical Outcome Study has shown that patients who were involved more fully in their medical care had better health outcomes with fewer hospitalizations as one endpoint. Patients in their experimental group were given their medical record to review prior to the visit and given a copy of the medical record for that office visit to take home with them.

In my experience as well, patients who are given a copy of their medical records become more confident in their own actions, more compliant with medical regimens and in control of their health care. They are more involved in the medical decision making process, ask more questions, and understand their conditions and proposed treatments. They accomplish much more during a specialist visit as well. I believe that the simple act of giving a patient their record does more to actively involve the patient in the health care process than most other activities.

Suggestion and Research Opportunities:

- 1) Research the use of patient-held medical records. *The Savard Health Record* is one such model that has been developed by a general internist with twenty years of clinical practice experience. It has already been pilot-tested and is readily available in bookstores, on-line and appropriate for customization. Outcomes can be assessed.

- 2) Establish work or study groups with trained facilitators to implement the use of patient-held records which could be held in community settings such as schools and churches, advocacy groups such as women with breast cancer and during educational sessions offered by health care providers. (I am currently working with The Parrish Nurses to pilot such a program.) The record should include biographical information, information on past medical history, family history, medications, allergies, preventive tests and immunizations, and sections for storing original copies of test results, consultations, and discharge summaries.
- 3) Teach people how to read and understand their test results, consultation reports and hospital discharge summaries. For example, I have found that patients who are on cholesterol lowering drugs are much more compliant with diet and their medication when they know their target LDL and receive copies of their actual test results. (I teach people during seminars and workshops how to read and understand their medical records. I also give an overview of the same in my book, *How To Save Your Own Life*.)
- 4) Encourage every person to carry an emergency medical information card with them at all times. Everyone should carry an up-to-date card that lists their medical conditions, medications with doses and directions, significant family history, emergency contact and family doctor information, allergies, immunization status and information on an advance directive. By encouraging patients to carry this up-to-date information they will immediately become more involved in their health while making life-saving information available in case of an emergency or unanticipated visit to a physician's office. (The Savard Card is one such example.)

III. Researching Your Own Medical Conditions and Treatment Options

Whether you are a loved one is diagnosed with a new condition, about to undergo a test or deciding on the best treatment, knowledge truly is power. Today patients are deluged with information and misinformation from the media, print and Internet sources. Yet doctors have less time than ever to educate themselves on all the latest research, let alone enough time to help their patients learn all about their conditions and treatment options.

Problems around medications represent one of the greatest sources of medical errors. I am always amazed in speaking to a large audience that very few people understand completely the purpose of their medications, the goal of therapy and whether it was achieved (most patients on cholesterol lowering medication do not know their target LDL or whether it was achieved by the medication). Often doctors and patients fail to consider medication interactions and effects as the source of new or recurring problems. Doctors are often not aware of previously prescribed medications, their effects and actions when deciding on medications for individual patients.

Suggestions and Research Opportunities:

- 1) Patients should be encouraged and taught how to research and evaluate the available medical information whether offered through the media, print such as newsletters and articles, or on the Internet. Whether diagnosed with a chronic condition or prescribed a new medication or treatment, patients should be instructed to become as informed as possible about all aspects of the condition, medication or proposed treatment.

- 2) Patients should keep an ongoing list of every medication (whether OTC or prescription), dose, directions, date of starting and stopping and purpose, response and any side effects. Patients could peel off the medication label usually attached to each prescription and place this information in their medical record. This continuous list would be invaluable to treating clinicians and pharmacists to help in treatment and prevent medication mishaps. Patients should also read the materials provided on their medications and keep this printed information in their medical record file.
- 3) Patients who are diagnosed with a chronic condition or who need to take a chronic medication should be referred to a group or resource where they can receive appropriate education and training for the specific condition or medication in question. For example, when prescribing Coumadin, the patient and/or family member/caregiver should be specifically trained in the use and monitoring of this information. Much as a clinician is kept up to date by continuing education courses, a patient should undergo the same relevant to their condition or medication.

IV. Forming a Partnership With Your Doctor

Participating fully in one's health care requires a partnership between the clinician and patient. A change from the typical paternalistic "doctor knows best" model to one of shared decision making and cooperation is essential. In addition to trusting one's instincts, keeping your own medical record and researching your conditions, learning how to partner with your doctor is therefore critical. According to the work of Braddock who has studied doctor and patient discussions about routine clinical decisions (8), important clinical decisions are common in practice but rarely preceded by

substantive discussion. In 9 out of 10 decisions made between doctor and patient during routine office visits, the doctor did not discuss the issue enough to allow the patient to make an informed choice. It is evident that both patients and doctors need to be trained and skilled in the important process of clinical decision making. Both doctors and patients lack training in effective communication skills. As a result, patients often don't understand or even remember the proposed medical regimen and do not follow the advice of the clinician. Patients are often intimidated in the doctor's office and forget to ask questions or volunteer information.

Preventive health tests are important but often not discussed during routine office visits. A major determinant remains a physician's attitude and motivation toward the provision of care and availability of information systems to assist them. Patients primary reason for not getting necessary preventive tests is that their doctors didn't recommend that they do so. I have reviewed hundreds of malpractice cases where plaintiffs successfully alleged that their doctors did not tell them to get necessary tests. In my opinion, patients have the most to gain and are in the best position to take responsibility for keeping their own preventive health schedule.

Although a family history is very important in helping doctors counsel patients about health risks and need for particular preventive tests, this information is often inaccurate, incomplete or not available in the medical record.

Suggestions and Research Opportunities:

- 1) Patients should learn how to prepare for every office visit with the help of a health buddy. They should list their concerns and questions, bring their health buddy and medical records to each visit, and be encouraged to ask questions and tell their story.

Clinician recommendations for treatment should be discussed and recorded. Patients should be encouraged to engage their health buddy with them in the decision making process. (A pre-printed office visit form is available in *The Savard Health Record* or free from my web site www.DrSavard.com.)

- 2) Patients should be encouraged to keep their own personal health journal to remind them of recurring or new symptoms, questions to ask the doctor, or tests to schedule.
- 3) Patients should be encouraged to keep track of their own preventive health schedule that they defined with the advice of their physician. They should take responsibility for seeing that the necessary and mutually agreed upon tests are done. Doctors can support this process by reviewing the patient's personal preventive flow chart with them during office visits. Use of the personal preventive flow charts could serve as an important quality indicator for a practice.
- 4) Patients should keep their own continuous list of allergies and side effects of medication, making this information available to every treating clinician and pharmacist.
- 5) Patients should keep their own up-to-date family tree and make it available to clinicians and other family members as well.

V. Getting the Best Care While in the Hospital

When I started out as a nurse over thirty years ago nurses were plentiful and the average hospital stay was over a week. Today because of tremendous cost-cutting patients are admitted to the hospital only when absolutely necessary and for as short a time as possible. The nursing staff has been partly replaced by non-professionals who often do tasks previously performed by nurses. Resident or "house"

doctors often have little information about the history and status of the patients they're seeing and a new brand of doctors called hospitalists are often taking over for the family doctor.

In the meantime, there are lots of practical things that can be done to give patients the best care possible under the circumstances.

Suggestions and Research Opportunities:

1) Patients should be encouraged to bring all their medical records, list of medications doses and directions, allergies and living will with them. Doctors do not always have ready access to a patient's medical history, especially if the patient is under the care of a new doctor. (And as my dad said following one of his many hospitalizations, you are too tired and sick to give accurate information over and over. Bringing your medical records and carrying at all times a card summarizing your vital health information can be a life saver.)

2) Encourage patients to have a health advocate or "health buddy" with them at all times. (My sister, my mother and I took turns being with my dad while he was recovering from heart bypass surgery.) The health buddy does not need to have special knowledge. The health buddy can ask questions, take notes and clarify exactly what is being done and why. Patients often think of this as a burden to their family or friends. In my experience, in time of need, family and friends are eager to help in any way they can. They just need to be told how.

3) Advise patients to identify the doctor in charge. A patient may see multiple providers, including their family doctor, any number of specialists, surgeon or anesthesiologist...and an ever changing cast of residents and other staff. It is not uncommon for patients to get conflicting information about what is going on. Each

patient needs a point person to explain what is happening and answer questions. Tell patients to ask the nurse who this person is and get his/her phone number.

4) A patient's health buddy should help the nursing staff as much as possible.

Encourage the health buddy to review with the nurses the "plan of care" listing dietary restrictions, tests scheduled, medications and any other special orders. This is the best way to be sure that mistakes do not happen. (I knew my dad was not to eat before a certain test and reminded the dietary person who mistakenly brought him a meal. This simple mistake could have prolonged his hospital stay.) A health buddy can offer to help the nurses and staff to make their jobs easier. The health buddy can keep their own "progress notes" listing their observations and questions in a tablet at the bedside for everyone to see. Physicians and nurses should review this information.

6) Encourage patients and their health buddy to get involved in discharge planning and to get a copy of their discharge summary. Patients are often sent home from the hospital still sick with new and complicated treatments. Patients should talk to the doctor(s), nurse and even a pharmacist if they are taking new medications. They should be reminded to ask about old medication they were taking before coming into the hospital. They should be encouraged to ask questions and have their answers recorded (this is a good time to consider using a tape recorder with permission) or written down if a health buddy is not in attendance. Patients should ask their doctor for a copy of the discharge summary and give her a self-addressed stamped envelope to remind her of the request. Patients who have undergone surgery should ask their surgeon for a copy of the operative summary as well. This summary would be of great help to future doctors and may not be available in a family doctor's file.

Finally, as the discharge summary and operative report may not be available for a few weeks, patients should ask for a copy of any important tests or findings such as EKG, blood work or x-ray's. They may be important to a doctor in case of a problem after the patient is discharged, especially if the summary is not yet available and the patient was not seen or treated by their family doctor while in the hospital. (My friend insisted on getting a copy of her sister's EKG and heart catheterization report upon leaving the hospital because she was admitted to the hospital on an emergency basis while on vacation many miles from home. She developed chest pain while en route home and the reports helped her doctors know how to treat her.)

Summary and Conclusions

Patients are our greatest untapped resource in addressing the widespread concerns about safety. The health care system has become increasingly complex and fragmented and multiple mishaps have occurred as a result. My hope is that by recognizing the patient as the central character in health care and involving them fully, we will usher in a new era in which patients would routinely archive their medical records, have confidence in their instincts, research their conditions, participate fully in medical decisions, and shoulder the responsibility for prevention and adherence to medical regimens. A fully involved patient would not only reduce medical errors, but would lead to the necessary and long-awaited changes in the doctor- patient relationship.

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