# TBD

*by Charles Hoes*

I was called home from the last conference because my wife had been taken to the emergency room (ER) with a seizure that turned out to be caused by an aggressive, non-operable type of brain cancer. She has since experienced three bouts of seizures resulting in transfers to a number of places: emergency room (ER), Intensive Care Unit (ICU), rehabilitation facility, and home. She spent about a half of the last two months in the hospital, with me sitting next to her side many hours a day. She is currently living at home undergoing a lengthy treatment of radiation and chemo therapy. She is sleeping much of the day. While she sleeps I have enough free time for me to write this article. Of course we are hoping for the best. It has been a pretty rough road so far.

This series of events and hospital stays has given me a lot of time to observe the patient-staff interactions of a small slice of the healthcare system from the "System Safety" point of view. There are many excellent papers on many safety aspects of the healthcare industry, including Dev Raheja's extensive writings about many of the system safety issues found with health care facilities. His many "System Safety in Healthcare" articles in the Journal of System Safety cover a wide range of topics, from the importance of system safety analyses for medical hardware to the "softer" human factors issues of providing healthcare. His articles are an excellent source of information, considerations and recommendations for improvements across the field of healthcare. In this article I am looking at the problems from a slightly different perspective, that of a "user" of the healthcare system.

My family's health insurance plan covers a wide (but not all inclusive) range of healthcare services through a large hospital chain. The general approach that they use to manage the patient's needs is to assign a General Practitioner (GP) to each member. The GP takes care of most common healthcare needs, and acts as the central hub connected to a system of specialists through referrals; except when entering the system through the ER, in which case the responsibility for providing referrals to specialists seems to change as the situation progresses.

During "normal" use I find the approach of always going through the GP to access specialists awkward and frustrating because it inevitably results in long delays and multiple doctor visits before obtaining a referral to a specialist. This approach of treatment by the GP first, with referrals for cases that are outside of the GP's expertise is understandable in the sense that it provides a means for limiting access to the more expensive services of the specialists, but it is frustrating when you know which specialist is most appropriate and have to "get permission" to receive services.

One of my observations while sitting and watching has been that there is a very strong tendency to limit care options to those things that are covered by the health care plan, rather than those options that would be most beneficial for my wife. There was very little "thinking outside the box" to other options that might not be covered by insurance, or provided by this particular health care system. The decisions seem to be about whether or not something is covered rather than finding the best solution. Since we are in our "Medicare Years", their approach almost always reverts to what services are covered and "allowable" by Medicare. Part of my frustration is that we are not financially limited to just what is covered, my wife and I spent fifty-five years building a financial cushion sufficient to withstand significant health care expenses – only to have our options limited by a healthcare plan designed to comply with Medicare limitations. We don't even

get apprised of other options that are available outside of the plan. There is a constant limitation of suggestions, recommendations and potential options because of this "wall" created by the limitations of "the plan."

While these types of problems are frustrating, expensive and achieve far below "optimal" healthcare outcomes, they pale in comparison to the much larger problem of extreme "siloing" within the system. My wife's condition(s) result in many different groups working to help her during the same period of time. She is in need of parallel treatments, not serial treatments flowing from one silo to the next .The list of involved groups includes (but is not limited to) the initial Emergency First Responders, ER personnel and doctors, ICU staffing and doctors, in-patient staffing and doctors, other doctors and staff such as the neurosurgery group, the oncologists, the palliative care nurses, the hospitalist(s), separate hospitals such as those doing rehabilitation services (i.e.; physical rehabilitation, occupational rehabilitation, speech therapy, social services), cardiologists, home care professionals and more. Each of the various facilities has their own administrators looking after the "wellbeing" of the organization (apparently mostly concerned with staffing and resource issues). Within each location (e.g., ER, ICU, Rehab Facility) there are other subgroups for nursing, nutrition, facility cleanliness, laundry, doctors, etc. Each of those subgroups also include managers that look after the needs of that group. What is missing is someone looking after the care of the patient!

Medical records within the main hospital system are highly computerized and available to those with a need to know in that system. Great attention is paid to making sure that this medical record system is up-to-date and filled with the detailed information concerning what actions have been taken. The medical record system contains the details of the care including vital signs taken many times a day, the medications, schedules, details of bowel movements and trips to urinate, the type and quantity of food eaten, times of visits by nurses, doctors, technicians and more. These details make up the "medical record" but it is unclear how often users have the time or the focus to know what it contains or means. The record has a great amount of detail, but perhaps not enough summary/interpretation/knowledge. One of my main roles while sitting and waiting was acting as a "hub" for information. The people (doctors, nurses, therapists, etc.) that came to check and evaluate always wanted to know what was going on with the other specialties; asking me what the various doctors and nurses were finding and describing, what "the plan" was, and a high level description of how things were going. It was clear that they weren't just being friendly; they often didn't know much about the specific "system" consisting of my wife. They changed shifts, changed schedules and changed patients so often that there wasn't sufficient continuity or knowledge transfer. There was a brief hand-off between shift changes, but clearly not in sufficient depth or detail to fully understand her situation. For example, the nutrition folks would bring a meal and put it on her tray for her without opening containers or taking the shrink wrap off, and leave to go onto their next delivery. They didn't know that she couldn't use her hands, so she couldn't get to the food.

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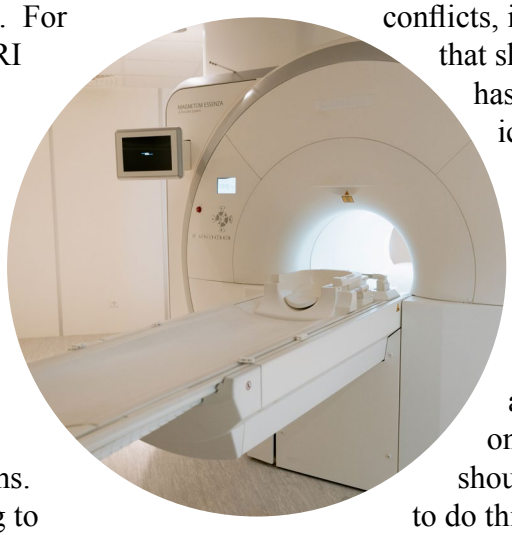
She could handle a fork and spoon well enough to eat, but couldn't get past the shrink wrapping to access the food. She was always a "new" adventure for each person. It was clear that they really needed someone to add in the "other" details that weren't in the medical records, or that are just too difficult to tease out from the sea of details. (Of course, I would open the containers for her when I was there, but it wasn't unusual for me to come back from a break to find unopened food on her tray.)

The lack of communication and continuity is a serious problem within the organization, but becomes far worse when outside organizations come into the picture. For example, her first stay at a hospital was an out-of-plan hospital in a different town. They had a sophisticated medical record system, but a different one from "our" hospital; therefore there was no easy way for the doctors to communicate. For example, I had to hand-carry the MRI DVD disc from one hospital to the other so that the second neurosurgeon could see the original scan to determine what had changed. It was up to me to make sure that the neurosurgeon was aware of its existence. In addition to the disc, I carried a subset of the medical records to physically hand over to the next hospital because it is difficult to communicate between systems. The same thing happens when going to an "outside" service provider for the radiation treatment. I had to meet with doctors on both sides so that I can tell each what the other is seeing and doing. They don't have an automatic way of seamlessly communicating between facilities or organizations. "My" hospital oncologist provides a referral to the "other" facility to provide treatments, but gets little or no feedback on progress or status.



While the hospital has a fancy computerized scheduling system for appointments and the like, there is no way to tie in the "outside" services and schedules. The folks that are providing at home services (such as rehabilitation) don't have access to the schedules of the other providers. I have to work with each and every appointment to find a space where I can fit it in, there is nothing like an on-line scheduler to allow me (as the patient representative), or other providers, to add in their scheduling constraints. It is a constant frustration, one that most patients would be unable to navigate without a dedicated, full-time, helper such as myself. My wife couldn't do any of these things – after all she has brain cancer which is sort of interfering with her cognitive and physical abilities. Most patients have issues that make it difficult, or impossible, to actively participate in the care system beyond doing what they are directed to do. Depending upon the patient to take care of a huge portion of the "logistics" problem doesn't work effectively or efficiently.

In summary, a huge hole in the health care system is the lack of a patient "advocate" within the system. Someone needs to be assigned to each patient to make sure all of the details are working and coordinated properly. This must be someone who is knowledgeable enough to recognize when there are conflicts, incompatibilities, and deviations that shouldn't be happening. Someone has to be monitoring things like medications, vital signs, appointment schedules, missing needs, etc. I am attempting to do this for my wife but I don't have the knowledge, the time (I can't do this 24/7 as is needed), and access to the detailed medical records. I am mostly blind and ignorant, meaning I can pick up on the things I can, but not all that I should. The GP might be in a position to do this, but in this case she doesn't get the records, doesn't know what is happening, and doesn't have anywhere enough time to do that because she has a full case load of her "normal" patients. She wants me to update her on my wife's status now and then to find out what is happening and how things are going. She is depending upon me to do a job that I am not qualitied to do. During times of great stress (which have been common with my wife's condition) I am not emotionally suited to identify and understand the kinds of information that the GP, neurosurgeon, oncologist, cardiologists, and others want me to update them about.

Now that my wife has been discharged from the hospital almost all of her support has been eliminated. We have medicines to take, but not much else. I don't have the tools or knowledge to know how to do things like manage her pain, keep her nutrition appropriate

now that she has lost interest in food, make sure she is getting "enough" exercise now that she sleeps almost all of the time, what I should be doing to prevent problems associated with too much inactivity. The list goes on, but there is no easy place to turn to for help. I can call the "advice nurse" who generally helps make the decision of whether or not to go to the ER – but little else. I can contact her GP who has almost no knowledge of her specific issues or history with regard to her current problems, and just refers me to someone else. The oncologist gives me cancer related advice and information. The physical and occupational therapists only have advice on how to rebuild strength once it has been lost and the cause of the loss has been eliminated, rather than on what we can do to minimize the loss. The radiation treatment facility only checks to make sure the treatments are being performed on schedule. They tell me to make sure she gets enough nutrition and exercise, but offer no guidelines or details about what that means or how I might accomplish it. All of the various doctors treating her at the hospital are no longer involved because she is no longer in "their" department – I am left on my own without any advice, equipment or knowledge about what to do now or in the near future as her condition deteriorates. Each time she gets re-admitted, an entirely new set of people get assigned to her care, with almost no historical knowledge of previous conditions from a month ago. I don't have sufficient information to allow me to effectively plan ahead.

The bottom line is that their "system" doesn't seem to have a working system with regard to the patient. Their "system" works as long as she is within a narrow "silo" of concerns, but situations that cross into other "silos" (such as transferring from the ER to the ICU), or stretch over time, get missed or confused. Now that she is not in anyone's silo, she is in my care – and I don't have the resources or knowledge necessary to take care of what comes up. Even if she ends up going back to the hospital, or into a "skilled nursing facility", the problem of maintaining a unified, coordinated care regime will still be faced with the silo problem.