

Patient Portals—the Way of the Future?

The IU Simon Cancer Center patient portal research project

by Amanda Patton

What promise might patient portals hold for improving quality of care in the community setting? How might secure patient portals complement quality care as well as streamline access and communication between patients and their caregivers and cancer care providers? *Oncology Issues* talks with Anna McDaniel, PhD, RN, FAAN, principal investigator of a patient portal research effort underway at the Indiana University Melvin and Bren Simon Cancer Center in Indianapolis, Indiana. Dr. McDaniel is Chancellor's Professor and Associate Dean for Research, Indiana University School of Nursing.

OI. Can you describe the patient portal research project underway at the Indiana University Melvin and Bren Simon Cancer Center in Indianapolis?

Dr. McDaniel. The original project was funded by the Walther Cancer Foundation, a charitable foundation with a close connection to the IU Simon Cancer Center. The Foundation was interested in projects that would link together patients, the cancer center, physicians at their practices, and researchers at IU. I thought that my project was actually a perfect match. I had envisioned this kind of information source for cancer patients for many years, but this project gave me the opportunity to bring that vision to life. For this project, I have partnered with Drs. Charles and Barbara Given, researchers from Michigan State University who have many years of research on how to help people maintain quality of life during and after cancer treatment.

So for this research project, we took the work that they've been doing and brought it into the Web environment with the Internet as the delivery mechanism, if you will.

OI. Your project has two components. The first is the open access public information website (www.cancer.iu.edu/cancerinfo) that is available on the cancer center's website. This

site provides general cancer information and resources for patients and families.

And the second component is the secure patient portal research project that is piloting the use of a symptoms management system for chemotherapy patients.

Dr. McDaniel. Correct. We have the public site, which was already a part of IU Simon Cancer Center's website. We helped to redesign this content—general information that anyone might be interested in, basic information on diagnosis, treatment, prevention, symptom management, and so forth. We are continuing to revise and update that content.

Then, we have this other component that eventually—if it is incorporated into the cancer center's practice—would allow people to develop a username and password for secure access.

The first step was the symptom management research project. There are many information sources on the Web about cancer and the side effects of cancer treatment, but I wanted to develop a site that provided tailored information. In other words, the information patients need when they need it, so that they could access this information with less effort. We would tailor the information about their particular situation so it would be easily accessible when they needed it, but also bring the cancer center providers into the loop. This type of linkage is important because often people use the Web or read books separately from the information provided by the doctor or the nurses. The patients may ask the providers questions, but they sort of have to figure out all this other information by themselves. With our project, we wanted to add a component where we connected the physician practices and closed that loop.

OI. So one of the ideas behind the patient portal was to provide patients with the specific information they need at the time when they most needed it. You would do the infor-



mation gathering to hopefully reduce the need for the patient or the patient's caregivers to be searching for information.



Dr. McDaniel.

Anna McDaniel, PhD, RN, FAAN

Exactly. And as you mentioned caregivers, we have additional funding from the Walther Foundation to extend this project and now we have brought the caregivers themselves into the whole picture. So we have symptom management information that we give directly to the patient. With the patient's permission, we will share this information with the patient's family caregivers, as well as information specifically for the caregivers themselves. For example, information about what they can do to maintain their own health and questions they may have about coordinating care.

OI. *When did the project start?*

Dr. McDaniel. The original grant started in 2007, and now we have a two-year extension so we have another year. We have completed a number of studies. We've completed the pilot study of the symptoms management patient portal with colorectal cancer patients. For this study, patients would log on, report their information, and depending on what kind of information they were inputting, there was computer programming that would provide patients with information about what they could do to help themselves.

OI. *Patients would log in on a weekly basis, and they would answer questions about chemotherapy side effects they might be experiencing?*

Dr. McDaniel. Yes. They logged on once a week for eight weeks to report their symptoms. When they logged on, they would be asked a series of questions about common symptoms they might be experiencing. They would rate each symptom on a scale of 1 to 10, as well as how much that symptom was interfering with their life. An algorithm, based on the Givens' previous research, is programmed to deliver information based on the level of difficulty the patient may be having. If any symptom is ranked as high as 7 (out of 10), we send a message to the oncology practice so the providers are informed about the status.

The information the patient receives provides "tips" and simple instructions about what a person can do to help manage the symptom or when to ask for help. It is reassuring for people to feel that they can help themselves and know that their problems are "typical" and not unusual or cause for concern. In the mean time, between weekly reports, the patients could log back in at any time and they could access the information on their symptoms and any other symptom they want to know about.

OI. *How do the providers use the portal information?*

Dr. McDaniel. Providers participating in the study get an alert that says they have an important message about a patient. Once the provider logs in, they can see their entire panel of patients—only their patients—and they can then see which patient triggered the alert. In other words, providers can see the patient who has a symptom that is of concern. They can review any of their patients that are in the study at that point in time, and they can see a variety of trajectories of the symptoms across time.

This pilot is now complete, and we are in the process of analyzing the results.

OI. *How many patients participated in the pilot and how long did the study run?*

Dr. McDaniel. Fifteen patients participated in the pilot study. Each person participated for eight weeks.

We're about to start the second phase of patient portal research that will likely involve 50 patients of all types of cancers and their family caregivers. The difference between this pilot and the first pilot is that we're adding the caregiver component. The caregiver will also log in on a weekly basis. They will find information about what their family member is experiencing and how they can



help as far as symptom management goes. They will also be able to access information about some of the problems they may be experiencing as a caregiver. This second phase will launch relatively soon. We start recruiting in early fall.

OI. *Who is involved in your research team?*

Dr. McDaniel. Obviously we have people in nursing, not only nurse researchers such as myself, but the clinical nurses and the clinical nursing oncology specialists who have been helpful in helping us design the patient portal. The oncologists, our content experts from Michigan State (Drs. Charles and Barbara Given), and a colleague here on campus who is a medical librarian have all contributed to the project. Finally, we have a very special unique resource on campus, the Indiana University School of Informatics that we used as we developed the patient portal. We have technology specialists and multimedia programmers whose specialty is designing, developing, and testing interactive technologies. We also have people on our team who are experts in human computer interaction.

We used a community advisory team, as well as nurses and others to help us design how the patient portal should work and what kind of information patients would need.

Then we have a very rigorous testing process so that before we launch the patient portal we are sure that the program works the way we think it will and that people don't have problems using the system. We have designed this application—both the open access and the secure portal—with a user-centered design approach.

OI. *For the patient portal research project that you've completed with colorectal cancer patients, what kind of data were you collecting, what kinds of outcomes were you looking at in terms of that data?*

Dr. McDaniel. Well of course it's a very small sample, but we are looking at their symptom trajectories and if using the system helped decrease problems they were having. We are looking at their satisfaction with the healthcare system, and whether or not they used other healthcare services, for example, did they have to go to the emergency room because they were dehydrated. Our preliminary results are very promising.

OI. *Were you also looking at patient satisfaction or lack of satisfaction with this tool?*

Dr. McDaniel. That's one of the main areas that we are looking at. The patients were very happy with using the system.

OI. *In terms of possibly improving quality of care provided, what do you think the potential is for this type of tool?*

Dr. McDaniel. I think potentially—if the patient portal were in widespread use—we would have a way that our providers could look at symptoms and side effects that patients are having, across time. The patient portal might provide a way to communicate an early warning about the toxicities of the drugs that might interfere with the person's quality of life. These might affect the treatment plans in that

if providers know about a problem early enough they may be able to intervene so patients would not have to interrupt treatment. Certainly this tool would allow providers to check with the patient the next time they came in for chemotherapy and allow the nurse to get more detailed information, do a physical examination, or make a telephone call follow-up. So I think our patient portal offers the potential for early warning about the side effects of treatment before these get so severe that the patient would have to go off chemo for a couple weeks. Obviously, treatment interruptions are a serious concern if the patient doesn't get his or her treatment plan as designed.

OI. *How does a patient portal fit with the emphasis on providing high-tech care in a high-touch environment?*

Dr. McDaniel. I see it as complementary. For example, in a state such as ours where the IU Simon Cancer Center is located in the center of the state—patients come in for their treatment and then to go back to their homes, which may be scattered throughout central Indiana or even beyond. So patient portals, if they work and if they are in widespread use, would reduce people calling, leaving a voicemail message, and waiting for the nurse to call. When the nurse does call back, patients often miss the call.

Our nurses were really excited to hear about this project because they thought that ultimately it would reduce the "telephone tag" problem that patients have. The nurses felt that they could actually be more responsive, and the patients, I think, feel like they're able to let their providers know about their symptoms and have them addressed without being a bother or a burden. Patients are often uncertain about whether they should call their doctor. They ask themselves questions, such as *Is this normal? Or Should I call somebody or tell somebody?* The patient portal can provide that type of information, as well as information about when patients *should* call their doctor.

We first tell patients they should call the doctor or go to the emergency room any time they think the situation is critical. So the patient portal provides patients with critical information about when they need to be seen right away or heard right away. On the other hand, if the situation is not quite at that critical level, the patient portal still lets providers know that the symptom or problem is there.

OI. *Given that many cancer patients are considered elderly, was the portal designed with this patient population in mind?*

Dr. McDaniel. Absolutely, we designed the patient portal with the understanding that users were likely to be people who did not have much experience with the Web. We've designed the patient portal so that it's easy to learn, intuitive, and gets right to the heart of the issue. The patient portal provides the ability for the user to modify font size, and we've tried to incorporate usability for people who may have low literacy or visual impairment and yet not make it frustrating for the savvy users. ■

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