

Brad Dicianno: Thank you. Good morning. Like Dave said I'm the director of the Adult Spina Bifida Clinic at the University of Pittsburgh Medical Center. We have one of the largest adult spina bifida clinics and I treat a lot of patients with chronic illness, complex disability, and medical problems that are very difficult to coordinate and for patients to self-manage. So I'm very excited to show you some of our work in this area.

First just a little bit more about chronic illness. We know that the impact is huge. Almost 50 percent of people in the United States have at least one chronic illness and about one in five people have some sort of disability. Both chronic illness and disability are very expensive. They prevent gainful employment. They cost us over \$260 billion annually, so if there is a way to save money, this is definitely the area to target. For people who do have disabilities, and have chronic illnesses on top of that (which is about 25 percent of people with disabilities), additional chronic illnesses can lead to more disability and even death, and the fact of the matter is that right now we are unable to effectively manage or prevent chronic conditions in a way that's cost effective.

We have looked at some data -- just at preventable conditions -- in these populations. If we consider conditions that could be managed better in the outpatient setting -- bladder infections, pressure ulcers or bed sores, pneumonia in people who did not get vaccinated --the cost of these conditions is almost \$150,000 per person per year. This graph shows that the bulk of these costs are on the inpatient side. Over \$120,000 per person per year is spent on treatment in the emergency room or in the hospital, and this is just for conditions that could

have been prevented or should have not happened in the first place.

Today I'm going to talk quickly about spina bifida using that as an example of a disability where we have an opportunity to intervene. This is just one example. A lot of these concepts apply to different populations. I'm going to show you data from a successful program using nurses to actually deliver interventions face to face and then a way that we can extend or translate those interventions through a telemedicine approach using smart phones.

So a little background on spina bifida. It's a congenital disability. It results in permanent cognitive and physical disabilities. It was once thought of as a pediatric problem. More than 85 percent of people with spina bifida are living well into their later years. I have several patients who are in their 80s, and most patients are outliving their caregivers. Part of their cognitive problems includes having difficulty with carrying through some of the self care activities that they need to do every day to stay healthy. So a lot of patients need to be on a bladder program. They need to catheterize themselves. They need to take their medications. They need to check their skin to make sure there are no pressure ulcers.

Many of these conditions are infectious in etiology and are completely preventable. They account for about a third of hospitalizations overall, and 1 percent of the hospitalizations for these conditions actually result in death. The readmission rate for these conditions are very high, meaning patients are getting discharged and then they are bouncing back to the hospital for the very same problems again. They are also very expensive to treat. Nationally, these

patients cost three to six times more than the general population to treat. Each time they are hospitalized they cost about \$30,000 and they are hospitalized on average about four times per year, so total cost is about \$360 million (patients with spina bifida and traumatic spinal cord injuries). Locally at our institution we spend \$2 million every year just on preventable conditions in this population.

So here are some data from a face-to-face program that we started with funds from the Highmark foundation. We have been able to reduce preventable conditions from 30 to 50 percent. First these are data showing patients who are served by the Spina Bifida Association of Western Pennsylvania. The table is showing the incidence of some of these problems. Skin breakdown, 30 percent of patients, urinary tract infections 35 percent, and hospitalization 20 percent. And the data for the patients in my population in my clinic just getting standard of care is very similar. But then when we look at patients who got the additional wellness interventions through the additional services provided by nurses, we are able to reduce these significantly. We reduced hospitalizations down to 13 percent, skin breakdown down to below 10 percent and urinary tract infections down to about 16 percent and we've also reduced length of stay of hospital admissions.

So recognizing the success of that program, the UPMC Health Plan which is our university hospital's insurance division, actually funded a larger program. We now have a full time nurse practitioner working with us and we've instituted care modules with interventions in each of the areas to target a lot of these outcomes. But of course, the nurse practitioner has to go visit the patient, she

has to call them. She has to check in. It's very hard to triage and monitor all these patients all at once and the program will continue to grow as we have more patients.

So the way to approach this through telerehab is to deliver some of the interventions through smart phones. Our approach is unique. It has dynamic two-way communication between our wellness practitioner and the patients. On the patient side, the patient would receive a whole host or a suite of applications that are specific to their own problems. So for example, this patient needs help with managing medications, managing their daily skin checks, catheterizing their bladder and so forth so they are receiving daily reminders to do these things.

They are receiving real-time educational information from the nurse practitioner, but it's also a reporting tool. When patients receive a reminder, they are able to report back whether that intervention was carried out or whether they had a problem during that routine self care task. So here's an example. Let's say the person is carrying out their daily skin check looking at their feet, making sure there is not a pressure ulcer and they discover a new one. The patient can take a photo of it, indicate where the wound is, provide information about the wound and send that information back to their wellness coordinator.

On the other side, the wellness coordinator is monitoring a whole host of patients, triaging and monitor everything that's going on with them in real time. This system can alert her when a new problem pops up immediately. So here, she's been alerted that one of her patients found a new wound. And then she can go ahead and open that patient's chart, receive information about the wound,

track the wound over time and even send information back to the patient.

In traditional care, these preventable conditions cost about \$150,000 per year per person. Our face-to-face program has saved more than 50 percent of that cost and we believe that the telerehab approach is going to save even more because it allows our coordinators to be more efficient in delivering the care and saves most of the travel costs associated. We are in usability testing right now, so we have developed a whole suite of apps for this specific patient population. We are doing accessibility and usability testing on those. We are going to be rolling them out into a controlled clinical trial next, and then once we go through the clinical trial we'll be diversifying our app portfolio and developing more apps so we can roll this out to other patient populations.

I just wanted to recognize my partner on the project, Andrea Fairman, our funding sources and partners which have included NIDRR and the Verizon Foundation, and I have listed my email address there if anyone has any questions or would like to discuss some more ideas (dicianno@ubicueinc.com).