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Financing Chronic Care Seminar: Specific Chronic Condition Studies and Models

Track: Health

Moderator: KAREN A. FITZNER

Panelists: IVER JUSTER
ROBERT D. LIEBERTHAL
STEPHEN P. MELEK
MARJORIE A. ROSENBERG

Summary: This session takes a fresh look at the issues related to "acute care focus" and the challenges of providing coordinated care for chronic conditions in the United States. This three-part seminar encourages a deeper exploration of this topic from a multidisciplinary perspective. Some of the topics examined include how to predict the incentives of costs for an individual with a chronic disease, current obstacles that stand in the way of health care system improvements for chronic illnesses, the impact of the aging U.S. population on the chronic and/or expensive conditions most often included in disease management programs (e.g., heart disease, diabetes, asthma, psychiatry and chemical dependency), the comparison of health care cost trends between chronic and non-chronic condition members of a health plan, the prevalence of chronic conditions within the insured population and the influence of possible confounding factors (such as catastrophic claims) on trends.

MS. KAREN A. FITZNER: This is the wrap-up session in our chronic care seminar. I'm Karen Fitzner, representing Disease Management Association of America

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NOTE: Charts referred to in the text can be downloaded at: http://handouts.soa.org/conted/cearchive/neworleans-june05/089_bk.pdf.

(DMAA), and we're co-sponsoring these sessions with the Society of Actuaries. I really appreciate the opportunity to be able to do this, so thank you. I'm going to start by introducing Steve Melek, who has worked in the health-care field as an actuary for 30 years and who has been with Milliman U.S.A. for 14 years, where he specializes in behavioral health care. He has completed research reports for Milliman on various topics in behavioral health care, served on SOA and AAA committees regarding behavioral health care and is currently working on the AAA Mental Health Parity Subcommittee. He has spoken often at SOA meetings and other health-care meetings on various behavioral health-care topics. He is widely published, and I'm sure many of you are familiar with his articles.

The second speaker is Robert Lieberthal. Robert is currently enrolled at the Wharton School at the University of Pennsylvania, where he is working toward a doctoral degree in applied economics. For the past six years, he was an actuarial student and consultant at PriceWaterhouseCoopers, where he worked on post-retirement medical benefits, defined benefit pension plans, and benefit and compensation issues. Mr. Lieberthal has passed his SOA Exams 1-4 and earned a bachelor's degree in mathematics from Boston University.

We then have Marjorie Rosenberg, who is associate professor at the University of Wisconsin-Madison with a joint appointment in the School of Business, Department of Actuarial Science, Risk-Management Insurance and in the Medical School, Department of Biostatistics and Medical Informatics. Her research interests are in the application of statistical methods to health care and applying her actuarial expertise to cost and policy issues in health care. She's in the process of developing statistical tools that can monitor health-care outcome processes. Dr. Rosenberg teaches actuarial science classes at the School of Business at UW. Prior to her academic career, she worked in individual life pricing and product development for Allstate Life Insurance Co. in Northbrook, Ill.

As our discussant, we have Dr. Iver Juster. He works as the Medical Health Informatics Director at Active Health Management in California. With that, I'll turn it over to this wonderful panel.

MR. STEPHEN P. MELEK: Thank you, Karen. I didn't expect to be up here at this particular presentation when I submitted an abstract for the chronic care versus acute care call for papers from the Society of Actuaries, but it's nice to have the opportunity to give a brief synopsis of a paper that ended up getting submitted and approved. My paper is not per se a perfect fit for the "Studies and Models" title; it's more of a description of the state of affairs for treating depression and the need for creative innovation and coordinated care in the United States today. I think there's a drastic need right now, and hopefully my presentation will provide information for you to take back to your organizations to contemplate and perhaps pursue.

There are maybe 100 people in the room here. The facts are that 10 of you probably have depression either right now or may have it sometime during the

year. That's a fact, and most people don't accept that or aren't aware of that, but this is clinically diagnosable depression. It affects almost 10 percent of the U.S. population in any given year. Over a lifetime, one in six people are going to be affected. The cost of depression to employers—and this is not their health-care costs, this is from the American Medical Association—is estimated to be \$44 billion a year in lost productivity costs to the U.S. economy. Only 20 percent of that is from absenteeism, by the way. The other 80 percent is presentee-ism, or lost productivity in the workplace. According to the World Health Organization (WHO), this is a worldwide phenomenon and is only expected to increase across the world. The good news is there is great efficacy for treating depression with medical treatments, therapeutic treatments or a combination thereof. It's proven to be very treatable. The effectiveness as we hear from some of our other cost-effectiveness experts is a whole different story, but there are very effective treatment guidelines that exist. Early treatment is very important and can prevent recurrences of depression in the future, but it is a chronic condition for many people who suffer from it, even though there are many others who have acute episodes, get treated, get well and never have a recurrence.

In spite of how prevalent this is, the astonishing fact according to the American Medical Association is that only one in five individuals are treated even with minimal effectiveness. There are minimum protocols for how long to be on antidepressants, how long to be in therapy and combinations of treatment before you can actually be considered well. In addition, part of the stigma associated with mental illness also applies to depression. When is a person well? If you've been treated for depression, it's not like having your appendix removed and you know when you're well. Treatment for depression or for other mental illnesses is very much a gray matter, which is part of the problem with some of the costing and other issues that are involved. But to put it in perspective, mental health spending in the United States from 1987 to 2000 went from \$10 billion to almost \$35 billion, and this is health-care spending. Spending on mental health and mental disorders is the largest of the top 15 conditions in the United States between 1987 and 2000; the increase in dollars was higher than diabetes, higher than cancer, higher than heart disease, higher than your favorite chronic condition. The No. 1 increase in spending in absolute dollars is mental disorders. The prevalence was No. 2 only to cerebrovascular disease, and there's a much smaller population of people who suffer from that disorder.

There are all kinds of other costs to employers for people who suffer from depression. Family mental health issues account for a quarter of all absenteeism to employers. Stress is the cause of one out of every six days that are lost. Employees with depression are twice as likely to take sick days as those without. And just a fact on drug use, even though this presentation is not about that, there's also a lot of money being spent by employers on drug use.

Let's compare the annual cost per capita and the average annual sick days of depression with some other major chronic conditions you would look at. Depression

accounts for anywhere from 50 percent to almost double that of some of the sick days taken by some patients with other chronic conditions. The per capita costs are comparable to diabetes and heart disease, and greater than hypertension and back problems. It's a very substantial issue here for employers and health plans and to the U.S. health-care system.

There are 100 of us in the room, more or less. Of all mental disorders, the prevalence is about 22 percent of the U.S. adult population. If 22 of us have a mental disorder in a year, what's going to happen? As few as three or maybe as many as six of us who have that will go to a mental health specialist: a psychiatrist, a psychologist or a clinical social worker. The rest will not get treated at all or will go to a primary care doctor. What other specialty has this kind of a fit, or should I say misfit, as to how the disease is treated by the health-care delivery system in America?

The behavioral carve-out was a great solution to some of our problems in the last decade or two. They did a great job at picking up the management of behavioral health-care costs and reducing the costs and getting them under control, and they carved out the specialty delivery. But is it part of the solution or is it really a part of today's problem? I think they plateaued as far as the number of members they cover in the carve-outs, the Magellans, value options and other carve-out companies of the world here. But they've contributed to great challenges we have with collaborative treatment and integrated treatment of depression for those patients that go outside of the carve-out network to get treatment for their disease. It's a silo effect, as I see it. There's very much a separation between physical health-care treatment and mental-health-care treatment, mostly across the United States, especially when there are carve-outs that are truly carve-outs. Even companies that have their own behavioral health-care subsidy companies that carve in still have very much of the same issues. It's very distinct with a lot of their systems, they're very separate: separated fee schedules, separated financial incentives, the whole works. There's very little collaboration that goes on between the psychiatrist and an M.D. in a primary care setting, between a psychologist and a family practitioner, for example.

Think about it. Maybe the average PCP might be 15, 20 years into his or her career. When was the last time he or she had a real education on identifying and treating mental disorders? It was probably one of their rotations back in med school 15 or 20 years ago. It made sense to them then, but where do they get continuing medical education on how to treat all of these patients? Maybe from drug reps who are presenting the latest and greatest SSRI or whatever else it might happen to be, but probably not a lot of focus in their continuing education is on diagnosing and treating mental disorders. But the interesting fact is that more than 50 percent of all mental health care is provided by PCPs, whether they know it or not. Two-thirds or more of all psychotropic drugs are being written by PCPs. I've seen some of the later numbers; it's pushing 80 percent. Not psychiatrists, but PCPs. One in every four patients who walks in the door to a PCP's office has a diagnosable mental

disorder, but very few of them are getting appropriate and adequate treatment for what's ailing them.

The issue is that mental-health disorders very often show up in different ways: back pain, chest pain, stomach pain, migraines. Eighty percent of individuals who ultimately are diagnosed with depression showed up in an office suffering from pain at first, and many of those patients do not get adequately diagnosed for what's ailing them. PCPs are not well trained to separate the physical symptom from the underlying mental disorder. If you think about it, how much time do you spend in a PCP's office anyway? How is the doctor going to be able to take those critical minutes and do much more than treat the symptoms and try to send you home happy with some sort of effort to make you feel better?

Melek Slide 1 on page 13 is a summary from our Milliman Health Cost guidelines that puts things in perspective. The top four lines are the inpatient and outpatient hospital and professional specialty behavioral health-care costs. By specialty costs, I mean those that are typically carved out of the health-care pie and sent over to a carve-out company. This does not include the PCP costs. "L/M" and "W/M" are our terms for loosely managed and well-managed care delivery. This is all costs: co-pays, deductibles, insured benefits, etc. And after you apply some of the co-insurance that applies to mental health care, the cost of the health plan might be somewhere in the \$3 to \$6 per member per month range. Some of yours may even be lower than that, and everybody thinks they've got a great handle on their behavioral health-care costs. But look at how much is being spent in PCP office visits and reflect on how many of those patients might be walking in with a behavioral disorder. These are just the office visit costs themselves. These are not the prescriptions they are going out the door with. This isn't the treatment for the side effects when they come back to the PCP. There are office visits and prescriptions for the side effects, because there are a lot of side effects even with the better SSRIs these days to treat depression. There's a lot more money being spent to treat depression beyond the typical carve-out cost.

Melek Slide 2 on page 13 shows a curve describing the relationship between patients in a primary care setting who complain of physical symptoms and the prevalence of a psychiatric disorder. The number of physical symptoms accumulates over time. It's a pretty dramatic relationship both on mood disorders, depression being the major one, and anxiety disorders or stress disorders. As patients go back, the likelihood of them having a disorder that is behavioral becomes quite high.

Depression is also very prevalent with other chronic medical conditions. One particular study defined a baseline of the well population that had a psychiatric illness at 18 percent. But patients with cancer, heart disease and chronic lung disease all have a higher prevalence than the baseline population. There are lots of companies out there that are treating most of those in some fashion through disease management. But how many of those companies are co-treating the

existence of depression for the patients who have co-existing depression with their cancer, depression with their heart disease, or depression with their diabetes?

In Melek Slide 1 on page 14, the first three layers are patients that have primary disorders of depression. The first three segments are the inpatient hospital or facility, the professional and the psychiatric drug spending for those patients. There's about \$50 per disease member per month that they incur for a facility cost, about another \$50 for professional services and about \$100 for drugs. It goes a long way toward telling you how much drug costs are increasing these days. But look at all the rest of their costs. These are not their costs to treat the depression. These are costs to treat other things that they're incurring. There is another \$200 for inpatient hospital stays, another \$150 for professional medical services and another \$50 for non-psychiatric drugs. So you can see for patients who suffer from depression, the magnitude of their medical costs goes up dramatically when they also have depression.

Melek Slide 2 on page 14 summarizes the trends in psychiatric facility costs from 1991 to 2001. The line at the top is psychiatric professional costs; the next line is the psychiatric facility costs. The line that starts at the bottom and goes up is the percentage of total health-care spending for psychiatric drugs, which has gone from about 0.5 percent to more than three times that. I think it's currently pushing 2 percent of all health-care spending. It's pretty dramatic to have the increase going up that rapidly.

There are all kinds of issues here, with problems that I can barely scratch the surface of in a short time, but there are some potential solutions out there. They are studies in controlled environments, but they are potential solutions to try to better collaborate and coordinate health care for people who have depression and other psychiatric disorders. I would suggest that one practical solution is certainly not restricting benefits. I'm interested if anybody wants to convince me that parity is a bad idea after the presentation. I think it's a great idea and I don't know why Congress is taking so long to get it through their heads that it's a great idea. The money just gets spent ineffectively in multiples in other settings, so let's get these patients the right kind of health care at the right time so they can get treated more effectively and not penalize them for having this disorder. There are also formulary considerations. You can look at your formulary, look at generics and look at step therapy.

PCPs need support. They need simple diagnostic tools to ask simple questions of their patients when they're in. One integrated solution would be to have a psychiatric nurse practitioner or a psychologist just down the hall if the PCP suspects that they might need to have a quick screening for depression or something else. Provide them with pharmacy reports so they know which of their patients for whom they just wrote antidepressant scripts has stopped taking their meds. The sad state of affairs is shown by a large study of treatment adherence rates for patients on antidepressants that we did. The minimum protocols are six

months of continued treatment after it starts becoming effective, and its efficacy starts at about two months. Meanwhile, the side effects start in a couple of days or weeks, and that's part of the problem. One out of every three patients did not refill their prescription one time, meaning they took the meds for less than 30 days. Minimum treatment is six months and then some. The percentage that effectively stayed on medication for six months was less than one out of three. So how much of that spending on psychiatric drugs that's coming out of the pockets of the employers and the health plans is effective?

Compliance programs, collaborative care programs and disease-management programs all can be a part of the solution that help PCPs. Employers can provide employees with more support through educational programs that educate the employees and their family members what depression is and what it looks like, as well as what it is not and what it doesn't look like. Providing wellness programs and health-risk assessments to employees on an annual basis can help give the patients the proper treatment.

I think the current behavioral health system in the United States and probably in many other places in the world is very fragmented and is contributing to the poor quality of care for depression in the United States. There's an increased need for new systems of collaborative and coordinated care. This is going to be a tough nut to crack, because there's a lot of resistance out there in the marketplace from all sorts of people, but the need is great. And with great need comes great opportunity for wellness initiatives and a better way of providing health care. Many challenges exist, but we can focus on getting new systems in place that give the patients the right care at the right time from the right provider. We can improve education both on mental and physical health issues and align incentives. The disincentives in place today are quite numerous between physical and behavioral health-care delivery. It is also important to improve patient adherence to the treatment regimens for drugs. Those things really work if you get the drugs to the right people, get them through the side effects and help them understand what's going to happen to them once they start taking them.

MR. ROBERT D. LIEBERTHAL: This seminar came from a call for papers on treating chronic conditions as chronic conditions, not in an acute way, and some of the financing mechanisms. I want to thank PriceWaterhouseCoopers, the New York Academy of Medicine and the New York Public Library, who provided me with electronic document access.

Diabetes is a chronic condition, which means there's no discrete start point. There's no point at which someone is a diabetic today and they were not yesterday. People who have diabetes can be easily screened and tested. There are certain segments of the population that have a higher prevalence of diabetes, whether for genetic reasons, lifestyle reasons or others, and screening in terms of blood sugars is a relatively harmless technique. There are a lot of preventive tools, so diabetes can be treated in a chronic way, in other words, to try to stop it before it becomes a very harmful condition to the person. Even for people in late-stage diabetes, some

things like exercise and improved lifestyle can be helpful. Some of these interventions can have a high positive return on investment. I don't necessarily mean that you could go out and prove it in a rigorous way, but you can see some big dollar and quality-of-life benefits. In terms of financing methods, this new consumer-directed model could have the potential to realize the full value of the chronic model of diabetes care.

It's a chronic condition. It's also progressive. It starts off where you can test positive for diabetes, but you might not have any symptoms or any very noticeable symptoms, then it gets worse over time. It's certainly a disease of aging. The causes are multifactorial: age, genetics, obesity, lifestyle. But the positive point here is that you can identify those people who might have a greater proclivity for developing diabetes. Then, of course, there are complications, including hypertension, coronary artery disease and stroke. These are the high-ticket, big-dollar items that we're all familiar with on the health side.

Reviewing treatment for diabetes, you have prevention, which the literature splits into primary, which is general diet and exercise and a healthy lifestyle, and secondary, some very targeted, self-management education programs. Some of them aren't cheap—they involve nurses and other practitioners—but they are shown to give some very high benefits in terms of improved health later on in life. Then you get into what you might call treatment if you are a layperson, or what the doctors call interventions. Primary interventions would be testing supplies, and secondary and tertiary would be drugs and dialysis. This is where we start to get into the complications, which are a lot more expensive than the disease was at the beginning stage.

Identifying costs of diabetes is complex. When someone dies and you put diabetes on the death certificate, maybe you could just as easily put congestive heart failure. It leads to a lot of complications, so it's hard to say what exactly are the costs of diabetes, because it is tied in with so many other different disorders. I tried to look at different treatments and their annual costs, although it's hard to do on a comparative basis. For lifestyle adjustments, I included prescriptive exercise, self-management programs, stop smoking programs, etc. There's a weight loss program called Optifast, which is somewhat costly because it's not Weight Watchers. They have doctors and nurses, and it's a very intensive program that involves a lot of counseling. So it costs a lot, but it's been shown to have really good results.

Moving on to testing supplies, you start getting some that are what I would call an annuity cost. You're paying these costs year after year. Then there are the prescription medications. Obviously, we know these are pretty expensive, and again, these are things that you're paying for year after year. Finally, when you get to surgery or outpatient procedures, you have things like bariatric surgery, which is surgery for correcting morbid obesity. Bariatric surgery comes in around \$30,000. Hemodialysis can be \$45,000 a year. A kidney transplant can cost \$100,000, which includes the cost of the transplant, transplant drugs, all the follow-up costs in the

first year and continuing to see physicians. Then you'll have lower costs in the coming years.

As I said, a chronic approach would be to treat diabetes as an ongoing disease rather than a series of discrete events. So instead of waiting for someone to have a heart attack, you would look at the blood sugar or the family history and try to attack the problem with lifestyle or maybe cheaper drugs early on. The rationale for this is not just the proof that you get lower morbidity and mortality, but diabetes is not an end-of-life disease. It's a disease that people can live with for many, many years. So if someone is otherwise relatively healthy, you get a lot of quality years out of the treatment. Again, these preventive tactics like diet and exercise are addressed again and again. They can be easily used once you identify people, and they are fairly successful at all stages of the disease.

If that is the textbook medical approach, what are the reasons that it doesn't happen? There are some medical reasons, including the failure to diagnose early on. There have been some studies looking at whether we should enhance the level of screening of certain populations. Some of the reasons that people might not get tested are if they don't have insurance or they're afraid of the doctor. There are a number of reasons, but obviously, the earlier you catch it, the earlier you can prevent it. Resource constraints are a familiar problem. Provider experience also enters into the picture. There is some evidence that providers or clinics that specialize in diabetes can have better health outcomes. I'm not necessarily saying that this is a better financial outcome, so we'll add that caveat. Lack of patient compliance continues to be an issue. People don't take their drugs because they're expensive or they forget. People don't exercise because it's hard. People don't eat right. I was writing this paper on diabetes and eating fast food every day because I didn't have any time, which maybe wasn't the smartest approach.

There is also at least one big financial barrier, which is that the payer, whether it's an employer or an insurance carrier, is not capturing the long-term rewards. A lot of programs, even preventive programs like self-management education, have high costs up front. People can change carriers or the employer that gives them insurance quite frequently, and then someone else is going to end up with that benefit. In order to illustrate this, I took a very simplistic model, bariatric surgery, which as I said is surgery for morbid obesity. It costs \$30,000, and that's just the cost of the reimbursement. That person who got bariatric surgery is completely cured of their diabetes, and as a result of this, the next year and in the future, their per capita cost drops by \$5,000. I assumed a discount rate of 5 percent, just because this is a good internal rate of return that some companies might look at for these kinds of projects. Then I varied the determination decrement, as well as the termination assumption, which is the assumption of the chances you'll leave either the carrier or your employer that provides your insurance in any year. If you stuck with the same employer or paid the \$30,000 yourself, then over 20 years, you're capturing a \$5,000 a year savings. That's a \$62,000 cost savings, and so this is a \$32,000 return on investment. As the percent termination gets bigger and bigger,

the savings don't get lost, but the person paying for the procedure doesn't see the savings.

So the question that I pose is what industry does your firm cover? What industry do you consult for or what kind of industries does your carrier cover? That might determine for you whether you want to cover bariatric surgery. This is a big subject in the news now. Some carriers say they will and some say they won't. Again, are there financing methods that we can use to capture these gains, because clearly the surgery results in improved health, so certainly it's a good thing to do. So we'd like to do this if we can.

As many of you are aware, there's a new financing method: consumer-directed health-care. People will have a financial incentive due to higher deductibles to do some of these preventive treatments. It gives the individual control for preventive care not covered by insurance. I think the idea of individual control and individualization is very important when we look at some of these chronic care methods. How many of us had the same doctor for five years? I know that I haven't had the same doctor for five months, so individual control and giving the individual responsibility is certainly a good idea. Though it is a little controversial, it might give us as insurers a chance to focus on our core competency, which is catastrophic claims, let's say claims over \$2,000. Can I prove that this is the case? No, but it's certainly an area of interest for me and I think it bears some discussion. Finally, as we saw earlier, employer-centered methods make certain treatments seem financially non-beneficial, so making a patient-centered versus employer-centered outlook might improve some of the health.

Again, there are drawbacks, which many people have pointed out. (By the way, I recommend the commonwealth fund research that is out there. I think that they're one of the main players at saying that consumer-directed is not a good idea.) It is unrealistic for lower-income individuals because, as we know, some of the costs of medical care are non-medical. There's travel time and income lost during recuperation, and insurance doesn't pick these costs up. There are big problems with information in terms of identifying quality care and the quality of providers. Communicating that information to laypeople is definitely a problem. Some people are working on that; we'll see how well it goes. Individuals may defer unnecessary care. We don't know if this is true, but we've certainly seen that. Misaligned financial incentives can lead to funny outcomes when it comes to health insurance. Individuals may do a bad job of assessing long-term risks.

I want to wrap up by saying that from a medical point of view, not looking at finances, diabetes certainly should be treated with this chronic approach. The literature bears that out, but unfortunately, employer-centered financing mechanisms don't capture this, so it's going to have to be a mix. Employers will have to consider whether their employee demographics support consumer-directed or not. Again, the utility of consumer-directed solutions is really going to depend a lot on employees' ability to utilize it.

DR. MARJORIE A. ROSENBERG: I'd like to acknowledge my co-author, Phil Farrell, who is a pediatrician at the University of Wisconsin and the National Institutes of Health for his support in this research. This presentation is based on work that we've done. It's a longitudinal clinical trial that began 20 years ago dealing with a disease called cystic fibrosis (CF). While it's not major prevalent disease, those with CF will develop diabetes and lung disease as they age, so it develops into one of these major diseases. I'd like to introduce a statistical method to think about a different way for actuaries to model these kinds of disease costs. I'll go through some background on CF and the objectives of this study, give you a little background of the data, and talk about the methods and the results.

CF is a genetically linked, inherited disease. In 1989, the delta F508 gene was identified as the major cause of CF. Since that time, 900 mutations have been identified, so people with CF could have one of 900 mutations. The delta F508 is a major mutation. About 70 percent of all CF patients have this delta F508 mutation. It affects pulmonary and gastrointestinal systems, leading to abnormal sodium and chloride transport. If tests don't find a double delta F508, they do a sweat test to see if your skin has too much sodium on it. If it does, then you're diagnosed with CF.

Because this disease mimics others, it's difficult to diagnose, which leads to a delay in treatment. The premise of this clinical trial that began in 1985 was that if you diagnosed this disease early, then it would lead to better clinical benefits. In the last five years, the project has evolved to talking about the cost-effectiveness of the screening program, and that's when I began in the study. So this part of the project is just a work in progress. It's the beginning of trying to assess the costs of treatment of CF.

CF affects about one in every 3,500 to 4,500 live births. There are about 35,000 people in the United States today with CF, and the median age at death is in the mid-30s. Back in the 1950s, the kids didn't get out of grade school, so it's an improvement, but not as much as we would like.

To give you some idea of actuarial-type research that's been done, there was a study in 1997 and one in 1998 that showed that the presence of health insurance decreased mortality and increased health outcomes. If you looked for people who had CF, if they had health insurance, then they got treatment and their health outcomes were improved. In a study done in 1999, children with major organ diseases such as CF showed a 54 percent increase in the length of hospital stays and a 79 percent increase in hospital charges as compared to children without chronic disease.

The objectives of this study are to use the data that we collected from the Wisconsin CF clinical trial to illustrate a modeling technique to predict hospitalization costs at the individual level. We want to do this so that we can include this in a cost-effectiveness model. The idea is if you have a group of

children who were screened for CF and another group who were just diagnosed through traditional means, meaning that they show symptoms or signs or somebody in their family has it, we will map out costs for those children by year of age and determine whether there was a difference in the screened group or the control group. These techniques can be transferred to other chronic diseases, so it's not that it's limited to CF.

As I mentioned, the data is from a randomized clinical trial where CF patients were accrued from 1985 to 1994. All the births in Wisconsin were screened for CF, along with other diseases at birth. For those who were in the screened group, they were told of the results right at birth. For those who were in the control group, the results were not disclosed until a diagnosis was made or the subject reached 4 years of age.

We have data collected from 1989 to June of 2003. We're going to be studying just the inpatient data in this particular phase, , so we have facility costs that were linked for the hospital stay as well as the physician data. There are two separate databases for the physician charges, X-rays and some other tests. One of the issues that we had deal with was that some of the data was truncated, because for children born prior to July of 1989, we had to deal with the fact that their costs were missing. We had censored data because some of the children left the study early, and we don't have care for them afterward. For periods in between, we have some missing data. All of those issues need to be covered in this modeling.

To give you an idea of the data, we have 77 individuals in the study. Rosenberg Slide 3, page 19 shows the accrual rate of the children over time and reflects people leaving the study. We reach our maximum at 70 in 1994 when the accrual ends, and then the children decrease because of withdrawal and other mechanisms. There was only one death in the study, so otherwise all the children are participating except for those who moved out of the area. I've isolated a subset of eight children who were high utilizers in the hospitalizations. I wanted to do a comparison between hospitalizations for these children who were high utilizers versus those who were not (Rosenberg Slide 3, page 19). From an exposure standpoint, they were 18 percent of all children back in 1989 and that percentage reduced as the accruals went up.

Rosenberg Slide 1, page 20 shows calendar year from 1989 to 2003 from year of age 0 to 18. As the children age, they move from one age group to another over each calendar year. You also have children leaving the study. We want to predict cost by year of age for the different groups, and so we need to use this kind of information.

To compare the hospitalizations, the hospitalizations for this group of high utilizers ranged from 75 percent up to even 82 percent of the total. Even though these children all have a chronic disease, CF, their utilization rates are quite different. There were children that had absolutely no hospitalizations; there was one child

who had 38 hospitalizations over this time period. So the question is: Can you lump all these children together to model costs from one year to the next? When you lump all people together in a chronic disease, they are very different. We call that heterogeneity. To model them as one group, they are going to be different. Withdrawals and new entrants especially will change the composition of the group.

As a summary, I came up with hospitalization rates by year. Overall it's 0.6, 0.2, but for this high utilizer subset, it could be as much as 3.9 per year. Rosenberg Slide 1, page 21, is the summary of the hospitalizations by person, by number of hospitalizations. You can see that 30 out of the 77 children had no hospitalizations over this period. As I mentioned, there was one person who had 38. The skewed nature of these hospitalizations shows how these children are different in terms of their utilization. We looked at their average costs per hospitalization by children, as shown in Rosenberg Slide 2, page 21. There was one child who had \$50,000 average per hospitalization, whereas the lowest cost for children who had some sort of hospitalization was around \$5,000. The bulk of them were between \$10,000 and \$20,000. At an individual level, there is a major difference in terms of the number of hospitalizations, and, if they go into the hospital, the cost per hospitalization.

To model this, I used the Bayesian two-part model. For the first part, we modeled the counts of hospitalization by year of age. Again, I'm trying to make this into the framework of a cost-effectiveness analysis. The second part addresses, given that the patient has had a hospitalization, how much that hospitalization would cost. The variables that I used are birth date (to get year of age), sex (I've used female as the indicator), active or withdrawal (so I can censor whether they are still in the study) and when they were diagnosed. If patients are diagnosed in the screened group, they're going to be close to birth. If they're in the control group, they could be diagnosed close to birth because of a condition called meconium ileus—a condition that shows a blockage in the intestine that is most often diagnosed right at birth. If it's not, it will be diagnosed later, but those children usually present a more severe form of CF. I used the screened or control group and then the genotype. If a patient has the delta F508A genotype on both alleles, he or she will have a severe form of the disease.

Initially we created a severity system where if patients had meconium ileus they were in one group, if they had a severe form of CF they were in another, and then we included the other children into the last group. We have about 70 kids who are still active in the study. Their age of diagnosis is a little over a year. About 40 percent are female and 50 percent are screened. Twenty percent have meconium ileus and half of them have the severe condition.

The two-part model is shown in Rosenberg Slides 2 and 3, page 22. For the number of hospitalizations, "i" is the person and "j" is the year of age. I've assumed that the counts per year of age are a poisson variable, which is labeled by one parameter, the mean, which is μ_{ij} . I've taken the log just to make sure it's greater than zero. You can see that the mean is a function of different variables.

We have the female, whether the person is screened, the current age, age at diagnosis, whether they have meconium ileus, whether they are severe, and then I have a random term that is by individual. This way, I can introduce an individual level variable that distinguishes predicting one person from another person. The second part of the model deals with costs. I include the sex and whether they are screened. This time, it seemed to fit better to take the square root of the age of diagnosis. Also I took into account both the square root and one over the square root to acknowledge that those children with meconium ileus who are diagnosed at birth are different than those who are diagnosed after birth. I wanted to accommodate both of those. And I had a similar type of model for the physician costs.

The results are something where I can get coefficients. I don't have p values, but you can look at the standard deviation relative to the mean. If you want to say that if you're within two times the standard deviation, then that's pretty good. The other way to look at it is that if we look at the sex variable, the one advantage of the Bayesian analysis is that you can actually predict the probability that this coefficient will be less than zero. In this case, it's about 86 percent that the coefficient for sex will be less than zero. When a coefficient is negative, it decreases the mean; when the coefficient is positive, it increases the mean. Here, with sex, if the subject is female, which is what that coefficient represents, it will reduce the number of hospitalizations per year. If she is "mi," then the cost of hospitalizations per year would increase.

I aggregate all these results and look at expected number of hospitalizations by year of age, by individual, again, frequency and the average number of hospitalizations by all the children. I took all the children in the study and applied these results. The patterned boxes are all the kids and the black boxes are just the subset (Rosenberg Slide 2, page 23). We said that those with the subset had greater hospitalizations. A majority of the model predicted that there'd be hardly any hospitalizations. If we blew that part up and showed it even further as in Rosenberg Slide 3, page 23, then you can see that there are still a lot of people who have fewer than 0.05 hospitalizations per year of age. The simple model has been able to take all the children, look at them individually and place them by category in terms of number of hospitalizations by age.

I pulled it together to see the costs, so it takes both part one and part two (Rosenberg Slide 1, page 24). The patterned boxes are all the kids and the black boxes are just the subset. Even though the subset of the kids had a lot of hospitalizations, they didn't have the most costly hospitalizations. This kind of model allows you to be able to separate out predictions by individual. I looked at an actual-to-expected ratio of just the facility costs. Most of the costs are between 90 percent and 110 percent of the expected costs. Overall, if I aggregated all the children, my actual-to-expected ratio was about 95 percent. If I just looked at the high utilizers, the actual-to-expected ratio ranged from 98 percent to 103 percent, so the model predicts quite well.

In conclusion, the model distinguishes results by individual. It allows for movement of individuals in and out of the group. It takes into account that some of the data was truncated. It takes into account that some of the data was censored and the fact that some kids withdrew from the study during that time period. It uses information that's readily available; it's not something that you have to go to patient charts to look at. It's what we call the first step in modeling cost-effectiveness of the newborn screening program. This would be useful in disease management or case management programs to predict costs, as it can be translated easily to other chronic diseases.

DR. IVER JUSTER: I'd like to give a little bit of perspective, partly as a physician and partly as somebody who does things with numbers as well, to chronic care in an acute-care-oriented system. Certainly our presenters on diabetes and depression touched on the fact that we call it a health care system, but it's not really much of a system. In acute care, it's fairly well organized as a system. If you break your ankle, you get an X-ray, have it put in a cast, have surgery, whatever. You recover and you're more or less done, unless you have some chronic damage, in which case now you have a chronic disease. But for the most part, acute care doesn't need quite the level of a system as chronic care does. In chronic care, there are so many participants, people are so different, the data flows in such strange ways and a lot of times it doesn't flow at all. So things get redone or misunderstood.

The focus for acute care systems is episodic as opposed to ongoing. In acute care systems, generally people either get better or they die. But chronic disease is progressive. There's a baseline, but there are exacerbations. If you have heart failure, you always have heart failure, but sometimes you have to go in the hospital and other times you're feeling pretty good. Some acute diseases can certainly be prevented, but in chronic disease, prevention is especially important. In diabetes, primary prevention might be maintaining a normal weight, and secondary screening might be getting a blood test to see if you have the disease. Secondary prevention would be avoiding complications by doing the right things. Those things are very prominent in chronic care and definitely require a systemic view. The orientation is single condition versus clustering conditions. People with diabetes tend to have heart failure, hypertension, high cholesterol, kidney disease and several other things, which are often called the cardiovascular cluster or cardiorenal cluster to include the kidney. Knowing that not only mandates a systemic view and systemic delivery of care, but also systemic monitoring and measurement of the costs and outcomes of various kinds of interventions. For example, as was mentioned in the diabetes presentation, there are other conditions that very often travel with diabetes. So if you ask what the cost of diabetes is, is it the cost of diabetes or is it the cost of diabetes and those other conditions?

There are 15 conditions that seem to account for the greatest majority of rising health care costs. Sometimes that's because people are getting older and there's more technology. In other words, there are more people with the diseases, it costs

more to treat the diseases, and sometimes it's just the prevalence. So if you're 50 years old today, you're likelier to have diabetes now than 25 years ago if you were 50 years old then.

This shows why we need a system both to screen for and prevent chronic diseases or manage them well when people get them, as well as to measure the costs of chronic diseases. In CF, for example, that's just as true. Once you know someone has CF, it's pretty easy to follow them. Where I went to medical school, most of the cystic fibrotics in Minnesota all went to a CF clinic, although if they lived 200 miles north of the city maybe they didn't. That's a nice focus.

Juster Slide 1 on page 28 shows the evidence-based medicine value chain. We're trying to improve the outcomes of people with chronic diseases and save money, or maybe even prevent them from getting the chronic disease. It's possible to prevent many chronic diseases. We start with new knowledge. The knowledge needs to get known to the physician and maybe to the patient who is bringing articles from the Internet to the physician. The physician has to then decide whether it's evidence-based or not, which doctors are rarely trained to do (certainly patients aren't). If you have diabetes and you smoke, you should take a drug called angiotensin-converting enzyme (ACE) inhibitor because it reduces nine different chronic cardiorenal events.

That was from the Heart Outcomes Protection Evaluation (HOPE) Study. First it had to be published, then doctors had to find out about it. (I'm going to leave patients out of the equation for the moment.) Then the doctor had to agree with it. How do you know this isn't just another study so the drug companies can make more money? We all know that negative studies don't get published very often. Studies funded by drug companies are likelier to show positive than negative results. Then, after you agree with it, you have to say yes, but the patient who has diabetes and smokes and is in front of you right now maybe doesn't qualify for this because he gets hives. People who get a certain kind of hives called angioedema actually shouldn't take ACE inhibitors, so you don't want to kill your patient. You actually have to remember all of this. The patient came in because he was coughing and had a fever. He just happened to be diabetic and a smoker. This is your golden opportunity, because you remembered reading this study, to put this person on an ACE inhibitor if appropriate and prevent these nine cardiorenal events.

After you've decided it applies to this patient sitting in front of you and you agree with it, then you actually have to take action. But the patient actually has to take the pill. We know that 30, 40 or 50 percent of people either don't fill their prescriptions in the first place or within a year aren't taking the pills anymore. Suppose there was a 20 percent drop-off between each step, which I think for some steps is pretty conservative. If you do the math, you'll see that something like 25 percent of the time the new evidence-based knowledge actually gets put into practice. That's very conservative. If you look at studies about decision-support systems and computerized reminders and studies where they tried to get people to

do the right thing, a lot of times that's what you'll see: about 25 percent of the time the right thing actually gets done. I don't want to be too pessimistic, but it's difficult to get the new knowledge, remember the new knowledge, decide if it applies to this person, then remember to do it anyway, then get the person to do it, then the person has to remember to do it, then you have to follow them up to make sure they're still doing it and it was really the right thing to do. Forget about them quitting smoking, managing their hypertension, getting them to run or walk or lose weight or deal with their heart failure. That's a lot to remember.

I need to be part of a system in order to get this to happen. Furthermore, if I'm looking at the costs and whether giving all of these people ACE inhibitors will actually save money, I have to remember that they are likely to have lots of other chronic conditions, especially if they have diabetes, heart failure or some of these things where people have associated conditions. I don't mean they're just getting older and tend to have more diseases. I mean that these diseases tend to hang out together, not just because people are getting older. They are actually physiologically and biologically intertwined.

When you navigate this labyrinth, not only from a medical prevention perspective, you also have to consider mental health conditions. There was an article recently in the *Journal of the American Medical Association* reminding us that people with bipolar disorder have 40 percent higher medical costs (not total costs, just medical costs) than otherwise risk-adjusted people without bipolar disorder. That's true for schizophrenics and to some extent for people with unipolar depression, the usual kind of depression. Why is that? It's partly genetic. Sometimes chronic diseases travel together genetically, including in their so-called mental health expressions. Second, if you're depressed or have bipolar disorder or whatever, you're probably not thinking as much about adherence to your treatment regimen as you might otherwise. Third, some of the medications used to treat these things themselves cause medical conditions. Some of the newer so-called atypical anti-psychotics that are used for schizophrenia and for bipolar disorder frequently cause weight gain and may cause or at least exacerbate diabetes. It's a tangled mess. The kinds of efforts in the CF initiative looking at how to predict the individual costs might be very relevant here. I really look forward to seeing how you would do that with coronary artery disease or these tangled messes of five diseases that always travel together. That will be very interesting to see.

MS. FITZNER: I want to thank our panelists very much. I think these were some wonderful papers and were well presented. And, Iver, I thank you for your discussant comments at the end.

MR. HOBSON D. CARROLL: My impression is that most health actuaries are firm believers in the idea that, especially for these chronic diseases that we seem to know a fair amount about (asthma, diabetes, etc.), there are pretty established medical protocols for the way you should be doing the maintenance treatment in order to save money in the long run. I think you have all presented a lot of great stuff that shows that, but I'm going to pick on Mr. Lieberthal because he's the one

who said something positive about consumer-driven health plans, or I think he was sort of implying that.

I would like to suggest that consumer-driven health plans, especially the ones that involve health savings accounts (HSAs) and high deductibles, are exactly the opposite of what we need to design as actuaries for plans and benefits to address chronic conditions. We should be designing plans that have condition-variable copayment policies, so that if you're a diabetic or an asthmatic, you should have to pay minimal amounts (less than the regular copayment) for the established protocol drugs and scheduled doctor visits. As it is now, you get punished. The HSAs, in particular, unravel the group underwriting and pooling principle that insurance used to be based on. You're basically creating a class system where people who have chronic conditions are being punished, if not directly because of money they have to shell out, because of the opportunity cost. They have to use the HSA to cover the deductible and their copayments for the doctor visits. I think it's a little bit backward and needs to be changed. I don't think that's consumer-driven.

MR. LIEBERTHAL: The point is well taken. When it comes to the design of some of the consumer-driven health plans, people are taking two approaches. One approach is the people who say that your deductible is \$2,000. You can sign up for an HSA and have a nice day. Sometimes people just end up with the high-deductible plan and don't get the HSA because it's hard to sign up for. I would also point out that with the HSAs, the people who benefit the most from putting the money away are those with the highest marginal tax brackets. It's certainly a problem.

I think, though, the more intelligent design that we're going to see is something like where you say here's the deductible, it's \$2,000, and this year we're going to put \$1,500 in the HSA for you, so the most you have to pay is \$500. This is more of an employer-based plan. As people have suggested, it will be like what has happened with deductibles—next year you're going to lower that \$1,500 to \$1,300 and \$1,100. It's not clear if that system works. It's not clear if they will work, but in order to make them work, there are some very particular design issues that we really need to hammer out.

MR. MELEK: I'd like to make a brief comment on HSAs and treating mental illnesses and depression. The statistics state that when a primary care doctor recommends a referral to a psychiatric specialist, the compliance rate is pretty bad. Fifty to 90 percent of the patients, based on the study, will not comply with the referral. There are all kinds of reasons why people do not want to seek treatment from a psychiatric specialist. This would be another reason, because if they have to pay for it all themselves, this other discretionary thinking that goes on. I don't think it's necessarily a good thing for psychiatric disorders.

DR. JUSTER: There's also a movement afoot called benefit-based copays, in which, if the treatment, usually a drug treatment, is shown to have specific value for the disorder the person has, so let's say ACE inhibitors for heart failure, the copayment

will be eliminated or greatly reduced at the point of service. Whereas if the ACE inhibitor were used when another drug could have been used just as effectively, let's say for high blood pressure, the normal tiering system would apply. Some of the work for this concept appears somewhere in 2002 in the *American Journal of Managed Care*. I think we're seeing more of this kind of thing, and it seems to dovetail well with consumer-directed plans.

FROM THE FLOOR: With the whole issue of disease management, there are the two prongs once somebody has been diagnosed with a chronic condition. The doctors don't necessarily do the care the right way and they don't know the right things because they don't have the right information, and the people are not compliant. We need to get the people not to have the conditions in the first place. We all agree with that. Has anybody done any studies on how effective public service messages are? Blue Cross in our state has the "Keep Walking" campaign.

MR. LIEBERTHAL: This actually answers another point that people use as a criticism for my example. In my example I was talking about the benefits to the person who pays, but the social benefit to paying for bariatric surgery for someone still remains. The benefit is still there. I think that there is some research about the stop smoking campaigns down in Florida—especially ones that were designed by teenagers for teenagers—that do show some social value in terms of the dollars that are saved by those campaigns through prevention.

DR. ROSENBERG: I would like to pick up on that. Certainly I think the walking programs have been more successful than other activities. One of the cities in Oregon had a "Walk an Extra Flight of Stairs a Day" program. The public radio system got involved in broadcasting this message. I believe the findings were that people were walking more stairs, but whether or not that behavior change lasted is not something that I've seen.

FROM THE FLOOR: This question is for Dr. Rosenberg. When the parents are told the kids are going to have a screening at birth for CF, it sounds like it's withheld, or do they sign something that they aren't going to know until later? Have you found so far any differences between the screened group and the control group as for severity or the general outcomes?

DR. ROSENBERG: Studies that like this have to go through intensive Institutional Review Board (IRB) screenings, which is required for human subjects now with the Health Insurance Portability and Accountability Act of 1996 (HIPAA). Parents signed a consent form to know. It was something where this was a trial to say status quo is being diagnosed through symptoms and signs and the new thing is the screening. It's not something that would have been done differently. To avoid bad faith or just to be upfront about it, that's why the decision to unblind at 4 years of age was made, so that regardless of the condition of those that were randomly assigned to the control, they would just know. There were children that were diagnosed at 4 years of age due to that unblinding that had skipped. Usually they are the milder

cases, so there are people who have been diagnosed in their 40s. It's a mild form of the disease and it probably wouldn't make any difference.

To date, what they have found is that there are nutritional benefits to finding the disease at birth. If you can diagnose it at birth then you can treat it, and you make sure that the child gets the enzymes and all the nutrients that he needs. They're actually followed four times a year because of the study, so they're getting a lot of medical treatment.

Another more recent find is that there is a cognitive difference between the child's brain when you're diagnosed earlier than if you're diagnosed later. There may be some long-term impact. For the survey itself, we're trying to go another five years to get the children to age 21, to get out of pediatrics and into adulthood. From a clinical and cost standpoint, what are the benefits of screening? There are only 12 states that actually screen for CF. Some of the states are waiting to see if it's cost effective for them to do it. Our study will be the study that determines the effectiveness of screening at birth for CF.

MR. CHRIS L. SIPES: I have the feeling that all these different diseases, treatments and proposals that we're looking at are beneficial to society and to the individuals. However, if we sit back as the group insurer or even on the individual insurance side, as actuaries trying to look at the price advantages of these, it puts us in a little bit of a quandary. The situation with CF is that they're living longer, so there is a longer treatment period. When I look at the overall cost, the insurance cost is going to go up, even though the quality of life and all is improving. When I look at parity on the nervous and mental side, I think about the fact that the majority of people, when they are referred to the behavioral health specialist or treatment, don't want to go there or take it. This is even before consumer-driven health plans are in place.

I think the reality is that if you have full parity, right now a lot of that treatment is taking place at the primary care physician (PCP). If they have a lot of physical problems, you're going to treat them there for the physical and mental problems. I think removing the physical problem or treating it, if you can get it cured, will help on the mental health side, but I'm not so sure that treating on the mental health side is going to relieve the heart problem as frequently. When I look at the overall puzzle, I see a total increase in benefit costs. Yes, there are savings for the employer for days lost, but if I'm not the carrier on that, if I'm just the insurance carrier on all of these programs, what I see is ultimately an increase in costs in order to treat them the right way to improve the quality of life and improve the system from the way it works right now.

DR. ROSENBERG: I agree that when you improve quality of life and you improve length of life you're going to increase costs. Another project that I'm working on is smoking cessation. It's the same kind of thing where you pay for people to quit smoking and they're living a lot longer. You're reducing some health care costs, but

in the end you're increasing. I think the viewpoint of those who do health services research (and in a way that's where I wear a different hat as an actuary) is that they don't represent an insurance company or health plan, but they look at a societal view and ask: Are we better off as a society? The whole idea of cost-effective analyses is to make choices. You do these studies. If I put a dollar here for this kind of disease, how much benefit do I get from it versus this? It's important to quantify, so that we make rational choices given resource constraints, knowing that if you improve quality of life you're probably increasing costs.

MR. MELEK: As a profession (maybe the concept hasn't been around that much), we would benefit greatly from more cost-effectiveness studies that are very well controlled on some of these different interventions that we're talking about. There has been research that does link physical health and mental health or the lack thereof. A lot of the premises in getting more effective care for people with mental disorders are that you'll waste fewer psychiatric drugs, you'll free up PCPs from their chronic ailing patients that keep showing up at their offices, you'll reduce some of the co-morbidity costs, and patients will take better care of themselves. A really nice before-and-after cost-effectiveness study would certainly go a long way to prove whether there is truly a medical cost offset for behavioral disorders or some of these other wellness interventions.

We've talked about how fragmented health care is. To me, it is so fragmented that we need to get it more integrated and work on some of these problems that we've talked about in this conference: the lack of electronic medical records, and doctors not remembering what they've learned and who is taking what drugs for what reason.

The other thing you did mention was the cost to the employer. We've seen the charts where it's going to break at some point. The employer is going to pull it or the employee isn't going to afford his copays or deductibles. There has to be a creative solution with a lot of aspects to it to prevent the U.S. health care system from breaking down in the next five years because of the total cost impact. If employers can subsidize health care costs through productivity or sick day savings, that's just another part of the potential solution.

MS. FITZNER: I think it's an excellent challenge to end on—that we have a creative solution called for to keep the U.S. system from breaking down. I hope you can all do your part.