

DIABETES MANAGEMENT™

The Complete Diabetes Disease State Management Resource

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Study shows shortfalls in achieving standards of care for diabetic patients

Vast majority don't get annual eye exams, total cholesterols

A major survey of over 2 million commercially insured patients, including nearly 16,000 diagnosed diabetics, shows the vast majority do not receive annual eye exams or total cholesterol tests, even though the American Diabetes Association guidelines call for such testing. The survey of patients who took insulin or oral agents was conducted by The Medstat Group of Ann Arbor, MI, and showed only 29% had annual eye exams and only 46% had cholesterol tests.

Medstat also measured triglycerides, high-density lipoprotein and low-density lipoprotein cholesterol, and HBA_{1c} levels, which company officials said showed similar low compliance, but they declined to release the statistics on the grounds they are "proprietary."

The survey showed similar shortfalls in practice for patients with asthma and congestive heart failure.

The results were "significantly below expectations," according to Medstat's medical director, **Louis Diamond**, MD, FACP. "We can't expect 100% will get the annual exams, but I'd like to see it in the 80% to 90% range. That would make me feel much more comfortable."

"This is an indictment of the system," says **Dennis Becker**, MA, MPH, the company's senior vice president. "Clearly, in terms of recommendations for diabetes care, there is a gap in terms of practice."

KEY POINTS

- Despite the available guidelines for diabetes treatment, patients are not getting standard diabetes care.
- In a survey of nearly 16,000 patient records, less than a third received annual eye exams, and less than half had annual total cholesterol tests.

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The reasons for the gap are related to lack of patient education, Becker says. "If the patients don't know what to ask for, especially those with chronic conditions, they won't get what they need." However, with a great deal of information now available on the Internet, "Patients are getting more savvy."

Diamond says the blame for the shortfall lies with the physicians, the health care team, managed care, and with the patients. "All of them have to work together to make these things happen," he says. "If only one plays a role, it becomes very difficult." However, he points out, "Most patients are compliant if you provide them with the information so they can understand why they should have a certain test."

Neither Diamond nor Becker say there is a plot to keep patients from getting the tests they need. "It's driven by a lack of the system monitoring itself," says Diamond. "If the systems don't know what or where the gap is, they're not going to fill it. It's as simple as that."

Medstat specializes in health care information and offers information bases, research, and consulting services to consumers, providers, managed care, and insurance organizations, governments, and research institutions.

"Our purpose is to bring more focus to the issues in health care and stimulate discussion," says Becker.

Tip of the iceberg?

Medstat's results parallel those of other researchers and of government payers, says **Ida Hellander**, MD, executive director of Physicians for a National Health Program in Chicago. The shortfall in eye exams and total cholesterol is a flag for serious shortcomings across the board, not only in the treatment of diabetics but management of virtually every chronic disease, she adds.

She notes that Medstat's study looked at those with insurance. "What about the 45 million people who have no insurance?"

"This is just the tip of the quality-of-care iceberg, says Hellander. "A lot of it is economic, because our system is so fragmented and so

profit-oriented. The whole system is not set up for quality patient care, it's designed to make investors money." She says managed care systematically excludes patients from preventive care for economic reasons since the average patient only stays in an HMO for 18 months. "There are a lot of financial incentives to deny care."

Aetna-US Healthcare takes exception to the accusations and points out its aggressive efforts to be sure diabetics and other sufferers from chronic diseases get the preventive care they need.

"We are across the board at above 50% of our patients getting the testing on scheduled as recommended by the ADA," says **Joseph Carver**, MD, Aetna's senior medical director in Bluebell, PA. He says that is a substantial improvement since only about 30% of diabetics were getting annual eye exams five years ago.

Aetna searched its databases back to 1994 to identify everyone with diabetes, and further identified everyone who hadn't had an eye exam in the past 12 months, says Carver. Patients were sent a letter urging them to schedule an eye exam. Lists of diabetics who had not received eye exams were also sent to their physicians, who were encouraged to make direct patient contact to be sure the exams were scheduled. Aetna also pegs compliance on diabetic exams to physician compliance ratings.

The company also has an education module, "Caring for Diabetes," which is offered to every diabetic patient in the system. Patients receive a letter of invitation to the workshop if they live close to a site where one is available. Those who are identified at high risk are also contacted by telephone. In addition, all of Aetna's diabetic patients are given blood glucose monitors. A general mailing to all diabetics is sent twice a year, and patients identified as moderate to high risk are contacted four times a year for office visits, labs and necessary tests. "It's a sophisticated system and it's working," Carver concludes.

[Contact Dennis Becker and Louis Diamond at (734) 913-3295, and Ida Hellander at (312) 554-0382. Medstat is a sister company of American Health Consultants.] ■

COMING IN FUTURE MONTHS

■ Hot tubs for treating Type 2 diabetes?

■ Dealing with human insulin

■ Women and diabetes

■ Bone mineral density for men and women

■ More on islet cell transplantation

Nurses want education to improve diabetes care

Health care professionals are rarely asked what would help them do their jobs better. So when a group of registered nurses got the ear of researchers, they had a lot to say. Their biggest concern: their need for more education to improve their care of diabetic patients.

Patricia B. McDonald, PhD, RN, assistant professor of nursing at the Francis Payne Bolton School of Nursing at Case Western Reserve University in Cleveland, surveyed 103 nurses.

McDonald says she was “appalled” when one-third of the original 200 general practice nurses solicited to participate in the study said they never provide care for diabetics, when actually, chances are very good the nurses are caring for patients with the disease but are unaware they are diabetics. McDonald says she was encouraged, however, when she found 41% of her respondents wanted more education in caring for diabetics.

More than a quarter of the nurses dealing with diabetic patients on a daily basis said they had no diabetes education updates in the past two to 15 years, and 63% said they had no practice guidelines available to them.

“The management of diabetes is changing very rapidly with the results of studies like the [Diabetes Control and Complications Trial] and the new drugs available,” says McDonald. “It’s hard to keep up with the latest developments in diabetes and dozens of other diseases, but that’s what we need to do to stay on top of this.”

McDonald says the answers to the 53 questions on her survey, some of them open-ended, were “very straightforward.” The nurses are requesting upgraded nursing education and inservice programs on unusual patient situations by certified diabetes educators, diabetes specialists, and nutritionists. Those nurses surveyed want to know more about these issues:

KEY POINTS

- RNs say they need more education to improve their care of diabetic patients.
- Many do not have access to practice guidelines.
- Informal and formal educational settings are suggested as solutions.

- blood glucose control during pre- and post-surgical procedures;
- phases of acute illness including infusing intravenous fluids with dextrose;
- sick day management of diabetes;
- management of hypo- and hyperglycemic reactions;
- management of complications and high-risk case management;
- counseling to help patients deal with the chronic nature of the disease and its long-term management.

Why did some of the responses to her survey upset McDonald so much? Of the original sample of 200 registered nurses working in inpatient settings, outpatient clinics, emergency departments, medical centers, and home health care, 33% said they never worked with diabetic patients.

“That’s simply not possible,” she says. “I don’t know why, because they did not respond to our query beyond that, but I can only guess that when a patient comes in with a sprained ankle, they don’t even pay attention to fact he is a diabetic. It’s a travesty that nurses can work for two to 15 years with no updates in their diabetes education.”

She lists the sources of education: local medical societies, seminars sponsored by drug companies in virtually every city of any size, on-line resources such as those offered by the American Diabetes Association (ADA) and the American Association of Diabetes Educators. (See ADA’s list of competencies, inserted in this issue.)

She offers only two explanations for nurses’ lack of awareness of diabetes: “Either they’re not interested, or they don’t think it’s important.”

“Diabetes has been here forever, and it’ll be here forever,” she says. “Many people would rather look at more exciting things like AIDS.”

McDonald says she had a jolting experience seven years ago when she visited a Veterans Affairs hospital. “I saw a 46-year-old African-American gentleman with diabetes sitting in a wheelchair — a double amputee who lost his legs to diabetic neuropathy. He said no one had ever told him this might happen. Something happened to me at that moment; I developed a passion about this — about educating nurses so they can educate their patients.”

Diabetes Management asked two other preeminent nurses in the field what they think nurses need to better care for their diabetic patients.

“I think this survey nailed a few things right on

(Continued on page 113)

On-line Resources

There's a wealth of information on diabetes out there, if you know where to look for it. The Internet can give you and your patients as much information about diabetes as you could possibly want. The experts say professionals can keep themselves up to speed, ask questions, get continuing medical education credits, answer patients' questions, and even direct them to sites where they can learn diabetes management skills themselves. *Diabetes Management* asked two experts in the field for their recommendations.

Michael J. Ackerman, PhD, assistant director for high performance computing and communications at the National Library of Medicine in Bethesda, MD, says there is a great deal of material available. Here are his suggestions for the most helpful sites:

<http://www.diabetesnet.com>.

This commercial site contains large amount of information, ranging from shopping at The Diabetes Mall to the latest news and research results to information on alternative therapies. It's easy to read, consumer-oriented with much information of interest to professionals.

<http://www.cdc.gov/nccdphp/ddt>.

This is the Centers for Disease Control and Prevention's diabetes Web page containing statistics, frequently asked questions for patients, and access to dozens of free government publications, both on-line and by mail. The site is professionally oriented, but may be helpful to highly motivated patients.

<http://childrenwithdiabetes.com>.

This consumer-oriented site for children and families of children with diabetes contains family-oriented material, and a section for kids that includes articles on diabetes camps and giving injections without pain. It also includes a unique section

where professionals answer individual questions. The site also contains several excellent medical dictionaries — of interest to professionals.

<http://www.niddk.nih.gov>. This Web site of the National Institute for Diabetes, Digestive and Kidney Diseases contains ordering information for a vast number of free government publications and materials on specific aspects of diabetes management. It's patient-oriented with a strong educational component that may be valuable to professionals.

<http://www.joslin.harvard.edu>.

This user-friendly consumer-oriented Web site of the Joslin Diabetes Center in Boston contains everything from research results to an extensive diabetes library to recipes and diabetes journals that can be printed out.

For professionals — CME courses are offered at these sites:

<http://www.pslgroup.com/DIA>

BETES.htm. This professionally-oriented site has voluminous reports on clinical trials and research results, discussion groups and a unique Internet resource update notifier through e-mail.

Rick Mendosa, a journalist in Aptos, CA, who is a diabetic, writes a regular column recommending on-line resources for the American Diabetes Association Web site (<http://www.diabetes.org>), which he says is perhaps the most helpful Internet resource for professionals and for patients. He agrees with Ackerman's recommendations on several of the above sites. Mendosa also has his own Web site, where he recommends dozens of other Web sites and posts some of his own writing on diabetes (<http://www.mendosa.com/diabetes.htm>). Ackerman also recommends Mendosa's Web site.

<http://www.diabetesdigest.com>.

This is an on-line version of the free patient-oriented magazine *Diabetes Digest*, distributed through pharmacies. It includes basic diabetes information for those just diagnosed.

<http://www.aadenet.org>. This is site of the American Association of Diabetes Educators, which includes a directory of the organization's 10,000 members, on-line conferences, and legislative updates, including the *Directory of Legislation and Statutes For Coverage of Diabetes Self-Management Education by Health Insurance*. This directory by state shows the status of mandated insurance coverage for diabetes education, equipment, and supplies.

<http://www.aace.com>. This is the Web site of the American Association of Clinical Endocrinologists, which contains guidelines for the management of diabetes.

<http://www.ndei.org>. The National Diabetes Education Initiative (NDEI) Web site for health care professionals is an on-line resource for medical education programs on Type 2 diabetes and insulin resistance. The site's features include "News Watch and Literature Alert," which provides information about the most recent diabetes research and news (updated every two weeks); "Sightings," which points out interesting features from other Web sites (updated every three weeks); "Diabetes Data," which features slides and lectures from the NDEI collection (updated every month); and "Events," which lists all NDEI-related and major international meetings (updated weekly).

Note: Consult only the sites from established medical facilities and organizations, as there is no regulatory body to oversee the information you find in cyberspace.

the head," says **Claire Paras**, RN, MBA, program manager for disease management at the Joslin Diabetes Center in Boston. "Diabetes is a moving target, since things are changing so quickly in this field. I feel like I am looking up the mountain in terms of the content of what nurses need to know."

Under Paras' direction, Joslin is reaching out to the offices of primary care providers to help their staffs update their diabetes management skills. "We need to find ways for caregivers to feel comfortable with their own knowledge levels, and that makes them confident in giving away that information to help their patients manage their disease," she says.

That means going to the providers' offices, being flexible on hours, providing small group sessions, often with lunchtime modules and roundtable discussions that offer ample opportunities for nurses to ask questions.

She calls Joslin's outreach education programs a "sort of nurturing process" to keep nurses updated. Paras says nurse burnout is widespread because of the enormity of the impact of diabetes in view of almost certain complications. "I am so struck by how profoundly dangerous this disease is," she says. "For nurses, it is extremely difficult to dealing with this disease that has no light at the end of the tunnel."

Even when a patient is doing everything right, he or she may still go downhill. "Nurses come here to heal people, and there's such a huge feeling of the overwhelmingness of it all," she says.

The lack of financial support for education programs for patients adds to the problem, says Paras. "Care providers and patients don't get a lot of help from insurers. Not much of that sort of assistance is reimbursable from insurance." And then, she asks, what does a nurse do to help a patient who can't afford supplies? "It doesn't matter how much education you get if the system works against you and your patients," Paras adds.

The most powerful solution might be the least formal training, says **Elizabeth Walker**, DNSc, RN, CDE, president of health care and education for the American Diabetes Association in Alexandria, VA. The key lies in almost continuous informal training in the clinical setting by staff nurses, certified diabetes educators (CDE), and whoever has the knowledge of diabetes, coupled with some additional formal training sessions. "Knowledge isn't enough," she says. "When it comes to diabetes care for themselves and for the patients, nurses need knowledge, beliefs, attitudes, problem solving, and coping skills."

Those skills are best learned in the clinical setting, she says, from CDEs or staff nurses who have more experience with diabetes and see it as part of their job to pass their knowledge on to their colleagues. Most nurses don't think of themselves as teachers, says Walker, who is also an associate professor of epidemiology and social medicine at Albert Einstein College of Medicine in New York City, but if each nurse becomes a teacher to colleagues and patients, the effect would be profound.

"In any health care system, it takes someone there to become a champion to make sure nurses in that system are kept up to date and to make sure that changes in guidelines are institutionalized. [Someone has to] get into the system so everyone is up to date on the newest techniques for teaching patients and the newest treatments," Walker says.

More formally, most health care systems have periodic training sessions in diabetes for nurses. Most managed care plans have inservice training in diabetes. And most have practice guidelines even though the vast majority of the nurses were not aware of them, says Walker.

There are on-line sources of continuing education and a vast amount of printed material through which nurses can receive continuing medical education credits. (See box, p. 112.)

And, in the most informal sense, says Walker, "Most general medical clinics have brochures and patient literature such as *Diabetes Forecast* in their waiting rooms. It's well-written, clear, and easy to understand. Staff nurses can learn from these materials as well as their patients."

[Contact Patricia McDonald at (216) 368-3345, Claire Paras at (617) 732-2400, and Elizabeth Walker at (718) 430-3242.] ■

Tricks for diabetic-safe Halloween treats

Kids can still have fun, despite their diabetes

During Halloween, most parents are concerned about the safety of the treats their kids collect while donning a costume. But for parents of diabetic children, the task becomes exponentially more difficult: How can these kids enjoy their holiday with their friends when there are so many restrictions to their diet?

For the past six years since her daughter Mollie was diagnosed with diabetes, **Jackie Singer** has volunteered from her Las Vegas home through the Juvenile Diabetes Foundation in New York City to help other children with diabetes join in all the fun of childhood. Ten-year-old Mollie has a powerful support team right in her family unit — her twin sister, Jackie, who is not diabetic.

Singer offers these suggestions to help children with diabetes prepare for the fun and temptations of Halloween:

- **Start early in the fall, just after Labor Day.**

Encourage children to get excited about the aspects of the holiday that don't involve sweet treats. Singer likes to build the excitement of Halloween over several weeks.

"We start talking about their costumes in early September, decide what they're going to be, and look through catalogs," says Singer. "It's really a big deal for the girls, and they get a real thrill out of ordering the costumes, planning their hair and makeup, and trying it all on when the package arrives."

The same thing would be true for boys, Singer says. They can get their thrills from planning their superhero or gory monster costumes and makeup.

- **For parties, the child can take healthy treats to share with all the other guests.** "Mollie and Jackie always take sugar-free cakes or candies so Mollie can participate in the good times right along with the other kids, says Singer. "Some of her classmates now say they like Mollie's treats better than the sugar-loaded sweets that are typically sent to school parties."

- **Work out a swap system for trickin' and treatin'.** Like most kids, the Singer girls must bring all their trick-or-treat candy home for inspection by parents before they eat any of it.

That gives Singer the perfect opportunity to swap with Mollie, piece for piece, sugar-free candies for the Hershey bars, M&Ms, and gummy bears that fill her bag.

"No big issue is made of it. She's happy with that," says Singer, "because she's not deprived of the sweets in any way." And, in the end, there's always room in a diabetic child's diet for a Snickers bar here and there. "I keep a few pieces out for those moments when she comes to me and says, 'Mom, I am really craving a Snickers bar.'" Singer says. "So we adjust her insulin and her diet so she can have one every once in a while. When we do that, she usually doesn't ask again for several months."

The important part of the whole plan, says Singer, is that the emphasis is placed on the fun and not on the sweet treats. "She feels in control, and, most importantly, she feels normal," says Singer.

Not only does Mollie have support from a loving family, she has a twin willing to make big sacrifices for her sister. Last year after Halloween, Jackie decided to give up candy for a year in solidarity with Mollie. "It hasn't bothered her a bit," says their proud Mom.

[Contact Jackie Singer at (702) 436-4981.] ■

Hypoglycemia can mean danger behind the wheel

Many drive when they know they are impaired

Do you warn your patients not to drive in an impaired state? It's not a matter of drinking and driving. Recent research shows a surprisingly large percentage of patients with diabetes are probably getting behind the wheel when they are impaired by low blood sugar. And some are consciously making the decision to drive even when they know they are dangerous on the road.

Recent research from the University of Virginia shows patients need counseling about checking their blood sugars before they get into the driver's seat. "We don't think of talking to patients about driving and hypoglycemia because it seems so obvious," says lead researcher **William L. Clarke, MD**, professor of pediatrics at the University of Virginia Health Sciences Center in Charlottesville.

KEY POINTS

- Many diabetic patients decide to get into the driver's seat even when they suspect their blood glucose levels are low.
- Large numbers choose to drive even after testing proves they are hypoglycemic.
- Health care practitioners should interview patients about their driving habits and make appropriate recommendations to help them recognize hypoglycemia and make correct choices about driving.

But Clarke and his colleagues were stunned to find that as many as 45% of Type 1 diabetics are putting themselves and others at risk by driving because they are unaware they are hypoglycemic. Others are getting behind the wheel even when they recognize they have low blood sugar.

"I don't know which is more frightening," says Clarke.

He says patients cite circumstances in which they feel they have no choice except to drive, even though they may be jeopardizing their own lives, their passengers, and other motorists. "They'll say they had to pick up the kids or they had no other way to get home from work or they had some pressing work obligation. [Other excuses include] they got out of football practice late after school or even that they had no glucose tablets or other way to bring up their sugars," Clarke says. "It's analogous to driving after a few drinks. Most of us have done that at one time or another without thinking of the possible serious consequences."

Shocking discovery

Sanford Mallin, MD, an endocrinologist in private practice in Milwaukee, says the study shocked him as well because Clarke's results will very likely translate to Type 2 diabetics and their far greater numbers on the road, although Type 2s have a lower risk of severe hypoglycemia.

Clarke's study was published in the Aug. 25 issue of the *Journal of the American Medical Association*. It has further significance because it measured the ability of Type 1 diabetics to recognize when they are hypoglycemic.

His 65 subjects were all Type 1 diabetics who drive and who routinely test at least twice daily. Each subject was given a hand-held computer to record data on symptoms, cognitive function, insulin dosage, food, activity, estimated and actual blood glucose levels, and what decision was made about driving.

Despite simulator tests that show blood sugars between 65 and 47 mg/dL lead to impaired driving ability, patients in the study said they would drive 40% to 45% of the time when they estimated their blood glucose was between 60 mg/dL and 70 mg/dL.

Worse yet, 18% to 38% of the time, participants said they would drive even when their blood glucose levels were at a dangerously low level of below 40 mg/dL. When they actually tested their blood sugars and were certain the levels were in

the 60 mg/dL to 70 mg/dL range, participants still chose to drive 60% of the time. And 38% to 47% chose to drive even when their blood glucose level was less than 40 mg/dL.

Clarke says as far as he knows, no one has done a study on the accident rates of diabetic drivers.

"If you talk to police, you find they don't ask a person if he has diabetes," says Clarke. "Most states do not have a diabetes notation on drivers' licenses, and a diabetic involved in an accident will not volunteer the information because he doesn't want anyone to know he was driving impaired."

Getting away with living dangerously

Additionally, many diabetics have gotten behind the wheel in the past when they knew their sugars were low and conclude they have "gotten away with it before, so they can probably get away with it again," he explains.

Clarke concedes that poor judgment is symptomatic of hypoglycemia because poor cognitive function is one symptom of the condition. So, Clarke says, it stands to reason patients may not make the best decisions about such crucial issues. "I strongly encourage diabetes health care teams to discuss driving with their patients," he says.

Clarke recommends caregivers take these tactics:

- ✓ **Ask patients how they determine if it is safe to drive.**
- ✓ **Recommend that they monitor their blood levels before driving.**
- ✓ **Advise them to plan their trips so they don't miss meal times.**
- ✓ **Suggest they always have glucose tablets or other sources of sugar with them.**

In addition, Clarke says, it is incumbent on health care teams to help diabetic patients better detect their blood sugar levels. "Help them recognize the symptoms, the moods associated with low blood sugar like drowsiness, irritability, and other mood changes," says Clarke. "Help them learn more about insulin and food peaks and keep diaries so they'll recognize when they are low."

"It's just not something we think about very often, but we must begin thinking along those lines and talking to patients about it now," says Mallin.

[Contact William Clarke at (804) 924-5897.] ■

Pancreas transplants: Are they a cure for diabetes?

Patients face a lifetime of immunosuppressants

More than 10,000 pancreas transplants have been performed worldwide since the procedure was first performed in 1966, three-quarters of them in the United States. And while a successful pancreas transplant rids the patient of diabetes, opinions vary whether a pancreas transplant should be performed before complications of diabetes set in and make a kidney transplant necessary as well.

One surgeon notes since more donor pancreases are available than are used, clinicians should think more about doing transplants early in the disease process. At what point should a physician advise a transplant?

Diabetes Management found two transplant surgeons with vastly differing viewpoints:

David Sutherland, MD, a pioneer in transplant surgery, is a staunch advocate of early and widespread use of pancreas transplants for diabetic patients before the cascade of complications starts. "Why would you wait? Why not do it before complications set in?" asks Sutherland, a professor of surgery at the University of Minnesota in Minneapolis and the director of the Diabetes Institute for Immunity and Transplantation, also in Minneapolis.

He argues that there is a relative abundance of pancreases available for transplant because virtually their only use is for diabetics. "Most of my patients are very unhappy with the burden of managing their diabetes. Just think of more than 3,000 fingersticks a year and 2,000 needlesticks a year — that alone is a very unpleasant business. The relative side effects of a lifetime of immunosuppressant therapy (including possible renal failure, tremors, and hirsutism) are minor compared to that."

KEY POINTS

- One transplant surgeon advocates early pancreas transplants for Type 1 diabetics before the onset of diabetic complications.
- On the conservative side of the transplant controversy, another surgeon says pancreas transplant should not be done until the patient is in need of a kidney transplant as well.

Transplant Statistics

Type of transplant	Patients waiting for transplant 9/99
kidney transplant	43,114
kidney-pancreas transplant	1,966
pancreas transplant	518
pancreas islet cell transplant	169

Type of transplant	Transplants performed in '98
kidney-pancreas transplants	965
kidney-alone transplants	11,990 (4,016 were living donors)
pancreas-alone transplants	253

Source: United Network for Organ Sharing, Richmond, VA.

And he explodes the myth that poor control is the sole cause of complications in Type 1 and Type 2 diabetes. "Even at an HBA_{1c} of 7.0, you'll get 20% of the patients with retinopathy, neuropathy, and renal failure," he says.

Practically all of the patients on the University of Minnesota's pancreas transplant list will get their pancreas transplants, Sutherland says, because the procedure is so underutilized. "There are 30,000 new cases of Type 1 diabetes a year, and there are about 5,000 pancreases available."

Yet, he points out, only about 1,100 pancreas transplants are performed each year, perhaps because doctors and patients aren't aware of the benefits of the procedure. "If a diabetic patient wants a pancreas transplant, he should get it."

Another view

At the core of the controversy is the lifelong course of immunosuppressants to prevent rejection and the unpleasant side effects of the therapy.

Transplant surgeon **Christopher Shackleton, MD**, associate director of the multi-organ transplant center at Cedars-Sinai Medical Center in Los Angeles, says he's in favor of a pancreas transplant only if a diabetic patient needs a kidney transplant and will need to be on immunosuppressants in any case.

"A pancreas transplant is a quality of life-enhancing procedure," he says. Its purpose is to

Woman chronicles journey to a diabetes-free life

A new pancreas and a kidney made Deb Butterfield of St. Louis needle-free and pain-free after 24 years of struggling with Type 1 diabetes and losing the battle against serious complications.

Diagnosed at the age of 10, she began to deteriorate dramatically at 29. She developed neuropathy, retinopathy, and nephropathy in rapid succession. A kidney-pancreas transplant failed after four months of pain and frustration.

A heart attack at the age of 34 came close to snapping Butterfield's fragile thread of hope, but it was followed by a second transplant that succeeded and finally left her free of diabetes and reversed the complications that had threatened to kill her.

Now, five years later, Butterfield lives a near-normal life with only a hint of the neuropathy that nearly crippled her. She's become a champion for diabetics through the organization she founded, Insulin Free World Foundation, dedicated to providing information on advances in clinical diabetes that can benefit those who suffer from the disease.

"I came back from the darkest of my days with diabetes to the freedoms, health, and sense of future that I had all but lost to diabetes' insidious attack," Butterfield wrote in her book, *Showdown With Diabetes* (New York City: W.W. Norton and Co; 1999). The book contains an intimate chronicle of Butterfield's victory over diabetes and detailed, yet simple, explanations of transplantation and current research in the field, which may be helpful to patients and health care professionals alike. ■

restore near normal intermediary metabolism, have some beneficial effects against complications, and reduce the chance of the recurrence of renal failure.

Shackleton says he simply doesn't think it's worth the risk of complications to transplant a pancreas alone and only considers a simultaneous kidney-pancreas transplant after carefully evaluating the level of risk. Beyond risks of a major surgery such as transplantation, the greatest risk with a pancreas transplant is a failure of the graft, which forces the patient to once again rely on the old defective pancreas.

[Contact David Sutherland at (612) 625-7600 and Christopher Shackleton at (310) 855-2641.] ■

Program aims to attract living kidney donors

Less invasive laparoscopic procedure reduces risk

Attracting living kidney donors for Type 1 diabetics is a major obstacle for any transplant program. Surgeons at Cedars-Sinai Medical Center in Los Angeles are offering a procedure that may increase the number of living donors willing to give up a kidney to help save a life.

Transplant programs in several regions are jumping on the bandwagon to use laparoscopic living donor nephrectomy because it reduces recovery time and complications for the donor and increases the number of donors who may be willing to give a kidney.

The surgery allows the donor kidney to be removed during a video-assisted, minimally invasive procedure through two or three small incisions. "This procedure offers much shorter hospitalization time, much reduced need for pain medication, a significant reduction in the need for blood products in the postoperative period, a much faster return to work, and most importantly, a greater willingness on the part of individuals to consider living donation," says **Christopher Shackleton**, MD, associate director of Cedars-Sinai's multi-organ transplant program.

The shorter recovery time is key for many prospective donors, says Shackleton, because they can return to work sooner than they might with a standard nephrectomy.

Another incentive which is "not trivial," he says, is that the resulting scar is as small as 2 or 3 inches, as opposed to a standard nephrectomy scar that is 12 inches long or larger.

"This procedure is fast becoming routine in transplant centers," says **Christopher Marsh**, MD, assistant director of the transplant program and associate professor of surgery at the University of Washington in Seattle. After about a year's experience with the procedure, he says, "There is nothing to indicate the procedure is problematic for either the donor or the recipient, but we'll need to look at it for several years to be sure."

For Marsh, there are several factors that make the laparoscopic procedure attractive. Among them: The hospitalizations time for the donor is reduced by as much as two days, meaning the donor can be out of the hospital two days after the procedure and back to work in as little as two

weeks. Part of the reason for the shorter recovery time, Marsh says, is the incision is made through the fascia, so the patient is spared the pain of an incision through the muscle.

The downside of the laparoscopic surgery, which is still under development, is a possible longer operating time and a possible higher risk to the donor kidney. "There may be a higher rate of failure; we aren't sure yet," says Shackleton.

Marsh says some medical centers are waiting to assess the success other facilities have with the procedure before they begin performing the laparoscopic kidney removals.

Living donors are the "gold standard for superior outcomes," he explains. Living donors are the donors of preference for kidney transplants needed by many diabetics because they are often relatives, so tissue matches are closer, reducing the risk of rejection. Five years after surgery, 85% of kidneys obtained from living donors are still working because of the closer tissue match, as opposed to only 50% of kidneys from cadaver donors.

However, Marsh says, recent research shows there's a higher success rate from any living donor, indicating a cadaver-donated kidney may be damaged by the process of brain death or by the elapsed time from death to transplant.

The ethical considerations of living donor kidney transplants are considerable, says Shackleton. "Our concern for the safety of the donor is paramount." A living donor nephrectomy is probably the only major surgical procedure undergone by a patient who doesn't need it. "We are meticulous in finding out if there has been any coercion, overt or covert," He says. "There absolutely can't be any arm twisting."

Yet, for the donor, the procedure is one of the safest major surgeries. "We've been doing these since the '50s, so there's a huge experience of people who have donated and lived long, healthy lives. The cumulative experience of complications is zilch," Shackleton says. And the possibility of failure of the donor's remaining kidney is very small, he adds, because of the intensive work-ups done before a donor is qualified. "There's really very little reason to be concerned about the donor's remaining kidney unless it is injured in an accident or something like that," he says.

Mark Deierhoi, MD, professor of surgery and director of the transplantation program at the University of Alabama in Birmingham, has some reservations about the procedure, especially in the hands of an inexperienced surgeon. While the

practice is becoming widespread, more as a "marketing tool" than as a procedure that has significant benefits for the donor, Deierhoi says, the University of Alabama does not offer the procedure.

"It's a highly technical procedure, and it takes about 100 of them before you really get good at it," he says.

His recommendation to physicians considering referrals for laparoscopic living donor nephrectomy: Ask how many times the surgeon has performed the procedure, and ask for the success rate. "If the surgeon has performed fewer than 100 or if the success rate is lower than you think is acceptable, look for someone else.

[Contact Christopher Shackleton at (310) 855-2641.] ■

Finalized rule coming on broader sharing of organs

Should geography determine your patient's chances of getting a kidney or pancreas transplant?

Absolutely not, says the Department of Health and Human Services (HHS), which is poised for final implementation of its regulations on organs for transplant. Even though the government's rule on organ allocation is a hot issue, say the experts, broad-based allocation is already in place and the new rule will not substantially change the system.

The core of the issue is that dozens of organ procurement organizations operate around the country, some with a population base as high as 12 million and others with a population base of as little as 1 million. The regulation is expected to make population-based organ allocation more equitable by creating sharing programs, essentially broadening some regions and shrinking others.

"Patients who need an organ transplant should not have to gamble that an organ will become available in their local area, nor should they have to travel to transplant centers far from home simply to improve their chances of getting an organ," HHS Secretary Donna Shalala said in a written statement. "Instead, patients everywhere in the country should have an equal chance to receive an organ, based on their medical conditions and the judgement of their physicians."

The Rule, as it is now commonly known, was

issued in March of 1998, but Congress imposed an 18-month moratorium on its implementation to allow time for comment. The moratorium expires Oct. 21, and the originally proposed regulation is expected to go into effect shortly thereafter with only minor revisions, according to HHS sources.

"Medical need and equity to access need to be balanced," says kidney-pancreas transplant surgeon **Christopher Shackleton**, MD, associate director of the multi-organ transplant center at Cedars-Sinai Medical Center in Los Angeles.

In fact, most of the Rule is already in place, says Shackleton, who has studied in detail three organ allocation banks. UNOS (United Network for Organ Sharing) in Richmond, VA, manages the national transplant waiting list and has a sophisticated nationwide computerized matching system. "The current allocation system is not found to be all that wanting," he says.

The issue is emotional, Shackleton adds. "From the lay viewpoint, the sickest patients should have greater access sooner," he says. "But we're looking at the utilization of a constrained resource, and we know from looking at the results, sicker patients have poorer outcomes."

Sanford Mallin, MD, an endocrinologist in private practice in Milwaukee, says residents of Wisconsin get a raw deal because of their proximity to Chicago and that metropolitan area's demand for organs and its comparatively less successful recruiting program.

"Wisconsin has the highest donor rate in the country," says Mallin, "And Chicago has less success in recruiting and a larger potential need for donors. It's like a vacuum sucking it up from us."

Mallin says a compromise was reached after Chicago hospitals got three donated livers from Wisconsin, but agreed not to take any more until the three livers were repaid from Chicago-area donors. The battle heated up after Illinois reneged on the bargain and both Wisconsin and Minnesota threatened to cut Illinois out of their region completely. Before that could happen, all parties agreed to a federally supervised sharing program, Mallin says.

He agrees with Shackleton that the organs should go to patients who have the best chance to survive. "It's a population-based controversy only in the sense each state wants to get its fair share, and I think the new rule will help make that happen," Mallin adds.

[Contact Sanford Mallin at (414) 276-1906.] ■

Pharmaceutical industry on track for Y2K compliance

With the year 2000 just a few months away, the Pharmaceutical Alliance for Y2K Readiness says the greatest threat to the drug stream is panicky consumers who could cause shortages of vital drugs such as insulin.

The Alliance, consisting of 18 professional organizations including the American Medical Association, the American Pharmaceutical Association, the American Academy of Family Physicians, and the National Consumers League, says the pharmaceutical industry is well-prepared for any contingencies that might occur on Jan. 1, 2000. "We do not anticipate problems in meeting the demands of customers for prescription

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medicines during the Y2K transition," the Alliance said in a statement published on its Web site.

"We know more now than we did earlier this year about what could happen, and there are alternative ways around those areas if there should be a break in the system," says **Susan Winckler**, RPh, group director of policy and advocacy for the American Pharmaceutical Association in Washington, DC.

In April, *Diabetes Management* reported that the country's two insulin producers were issuing reassuring messages while some organizations, such as the American Pharmaceutical Association and at least one major mail-order source of prescription drugs were recommending that patients get a month ahead on their medications.

Drug companies said they were concerned about their support structures like water and power supplies from surrounding municipalities and power companies, but they said those problems now have been adequately addressed.

The Food and Drug Administration (FDA) has confirmed that the pharmaceutical industry's Y2K plans are complete and adequate. The regulatory agency's Y2K statement says, "As a result of concerns related to Y2K, some consumers have discussed the need to stockpile or hoard drugs to ensure availability. This is not necessary. The FDA is surveying the pharmaceutical industry to show that the so-called year 2000 computer concerns will not affect the supply or availability of drug products. The pharmaceutical industry has put controls into place, which will ensure that a steady supply of medicine will continue to be available."

"Overbuying is the only threat," says **Phillip Schneider**, spokesman for the National Association of Chain Drug Stores in Alexandria, VA, an Alliance member that represents 31,000 of approximately 50,000 chain drug stores in the United States. Patients are advised not to stockpile prescription drugs and to refill their prescriptions as usual when they have a five- to seven-day supply remaining.

Some manufacturers increased production last summer in anticipation of extra orders, but industry leaders say there has been very little extra demand at this point.

"There's been an increased amount of information released by manufacturers and wholesalers about their preparedness plans, and it now appears that there is no need to overbuy or stock up on medications beforehand," says Winckler.

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country's two suppliers of insulin, says 99% of its product is manufactured near its headquarters. Lilly says it has reviewed readiness of all suppliers and developed backup plans.

The other insulin supplier, Novo Nordisk of New York, manufactures insulin at its plant in Clayton, NC. Novo says its Y2K preparation were 98% complete in August and expected to be completely in place by the end of September.

[Philip Schneider can be reached at (703) 549-3001 and Susan Winckler at (202) 429-7533.] ■

CE objectives

After reading this month's issue of *Diabetes Management*, the continuing education participant should be able to:

- Identify particular clinical, administrative, education or managerial issues related to the disease management of diabetes patients.
- Describe how those issues affect diabetes patients, diabetes management programs, and diabetes costs.
- Cite practical solutions to disease management problems associated with diabetes, based on overall expert guidelines from the National Institutes of Health, the American Diabetes Association, the American Association of Diabetes Educators, or other authorities, or based on independent recommendations from clinicians at individual institutions. ■

Nurse Competencies for Diabetic Care

The American Diabetes Association in Alexandria, VA, published the following competencies for nurses in 1993. Despite numerous advances in diabetes treatment and care since that time, these competencies are still applicable, says **Elizabeth Walker**, DNSc, RN, CDE, president for health care and education for the American Diabetes Association. *Diabetes Management* presents them here, as a starting point for nurses to assess their skills in caring for patients with diabetes.

Pathophysiology of Diabetes Mellitus

Describe the delicate balance in the relationship of nutrition, exercise, and medication to blood glucose control.

- Explain the major physiologic changes related to diabetes.
- Compare the effect of carbohydrate, protein, and fat absorption on blood glucose.
- Discuss the four main components of diabetes care as patient education, diet management, exercise, and medication.
- State how exercise affects blood glucose.

Discuss the risk factors for diabetes.

- State that there is an increased risk of non-insulin-dependent diabetes mellitus (NIDDM) in individuals with a strong family history, those who are overweight, and those of African-American, Native American, or Hispanic descent.
- State that the incidence of NIDDM increases with aging.
- Discuss the increased risk of developing NIDDM following gestational diabetes with failure to maintain ideal body weight postpartum.

State the major clinical manifestations of diabetes.

State the major differences between the types of diabetes in terms of pathophysiology, symptoms, and treatment.

State that psychological and physical stress can either raise or lower blood glucose and affect metabolic control.

Meal Planning

Describe the purpose of the meal plan in the management of diabetes.

- Explain the reason for consistency in amount, composition, and time of food intake from day to day.
- Select food within a recommended meal plan.
- State the possible effects of alcohol on the person with diabetes.

Describe the individual factors which influence nutritional meal planning for persons with diabetes.

- Recognize that dietary behavior changes may be the hardest behavior changes to make.
- Recognize that all persons with diabetes should be referred to a dietitian at least yearly.
- Recognize the importance of an individualized dietary plan.

Define the concept of food exchanges.

- List the diabetic exchange categories.
- Indicate appropriate serving sizes within exchange categories.

Physical Activity

Describe both the benefits and the risks of exercise for the person with diabetes.

- Recognize the psychological and physiological benefits of physical activity for people with diabetes.
- Discuss precautions to be followed prior to, during, and following any alterations in activity.

Insulin and Oral Medications

Explain the importance of regular oral medications and insulin use.

- State the recommended timing of taking insulin and oral medications in regard to meals.

Demonstrate the techniques for subcutaneous insulin injection.

- State the rationale for choice insulin injection sites.
- Demonstrate appropriate care of supplies (insulin storage, syringe disposal).
- Discuss the accepted technique for re-use of insulin syringes.
- Describe lipodystrophy, lipoatrophy, and hypertrophy.

State the types and availability of alternative insulin delivery systems.

State the differences in onset and peak and duration of action of the types of insulin.

- Differentiate between strengths, sources, types, and brands of insulin.
- State the rationale for the use of human insulin.
- Differentiate between intensive and conventional insulin therapy.

Discuss the mechanism of action of oral hypoglycemic agents.

- Discuss the side effects/adverse effects of oral hypoglycemic drugs.

Monitoring

Describe the therapeutic use of self-blood-glucose monitoring (SBGM) in persons with diabetes mellitus.

- Interpret the results of a random or fasting blood glucose.
- Discuss the importance of SBGM to state-of-the-art diabetes care.
- Recognize that one high or low blood glucose reading may not be significant, but patterns are the important information for long-term control.

Demonstrate the correct technique for capillary blood glucose monitoring.

- Discuss appropriate quality control for blood glucose monitoring equipment.
- Describe appropriate record keeping (insulin, meals, activity, glucose readings, hypoglycemia).
- Describe appropriate care of supplies.
- Discuss infection control principles in glucose monitoring.

Describe the significance of a glycosylated hemoglobin test.

Describe urine testing for ketones as a metabolic assessment when the blood glucose is elevated at approximately 240 mg/dl and higher and during sick days.

Treatment of Hypoglycemia/Hyperglycemia

State the causes and manifestations of hypoglycemia.

- Identify the signs and symptoms of hypoglycemia.
- State that when in doubt about hyper- vs. hypoglycemia, the nurse and patient should treat the hypoglycemia.
- State the rationale for the treatment of hypoglycemia.
- Demonstrate the treatment of mild, moderate and severe hypoglycemia.
- Describe the rationale for using glucagon to treat a severe hypoglycemic reaction.
- Describe the correct technique for a glucagon injection.

State the causes and manifestations of hyperglycemia.

- Discuss the symptoms and treatment of hyperglycemia.

Discuss the causes of ketosis, ketoacidosis, and diabetic coma.

- Explain DKA (diabetic ketoacidosis).
- Discuss symptoms and treatment priorities for DKA.
- Explain HHNK (hyperosmolar hyperglycemic nonketotic coma), symptoms, and treatment priorities.
- Compare and contrast DKA and HHNK.

Describe principles of sick-day care.

- State specific pre- and post-precautions of the surgical patient with diabetes.

Chronic Complications

State the guidelines for prevention of major complications of diabetes.

- State the rationale for keeping blood glucose levels near the normal range.

State the risk factors for developing major complications of diabetes.

- Acknowledge that people with NIDDM and IDDM are both at risk for the long-term complications.

Recognize the need to seek counseling for coping with chronic complications of diabetes when appropriate.

- Indicate how complications may affect both the individual and the family.
- Indicate body image changes that may occur, related to diabetes and its complications.

- Determine that persons with diabetes may be hesitant in describing sexual difficulties as a long-term complication of diabetes.

Discuss the major complications of diabetes.

- Recognize the early signs and symptoms of the chronic complications of diabetes.
- Discuss macro- and microvascular complications of diabetes.
- Discuss peripheral and autonomic neuropathy.
- State that persons with diabetes are at risk for dental problems.

State available treatment for different kinds of diabetes complications.

- State appropriate referral patterns for the early detection and treatment of complications of diabetes.

Foot Care

Describe the essentials of a nursing assessment of the foot.

- Demonstrate foot assessment.

Explain the rationale for daily foot care.

- State the importance of preventive care of the feet.
- Describe the relationship between wound healing, infections, and metabolic control of diabetes.
- Recognize the early signs and symptoms of infection.
- Describe the elements of the daily care of the feet that must be taught to persons with diabetes and their families.

Psychosocial Adjustment to Diabetes

Recognize that diabetes is a serious illness requiring extensive behavioral, medical, and education interventions.

- Recognize the significance of the demands that diabetes management has on the individual with diabetes.
- Realize that diabetes affects the entire family no matter what the persons' age at diagnosis.
- Describe how the diagnosis of diabetes can affect the lifestyle of young adults, middle-aged adults, and older adults.

Describe the adaptation process and individual coping styles as they relate to diabetes.

- Assess the patient's emotional responses to the diagnosis of the diabetes.
- Assess individual/family lifestyle activities and coping skills.
- Describe the importance of stress management techniques for the person with diabetes.
- Recognize symptoms that indicate the need for psychological counseling.

Impact of Diabetes on Children and Family

Identify appropriate developmental goals in relation to diabetes care.

- Recognize the importance of monitoring normal growth and development in a child with diabetes.
- Indicate the psychosocial and treatment issues related specifically to diabetes in childhood and adolescence.
- Recognize that the demands of diabetes management will change as the developmental needs of the child change.
- Recognize that family support and involvement is an integral part of successful diabetes management.

Demonstrate the correct method of insulin injections for a child with diabetes.

- Demonstrate holding the child during the insulin injection procedure.
- Recognize symptoms of hypoglycemia in the young child.

Recognize the importance of preventive health practices for children and adolescents with diabetes (e.g. smoking, alcohol use, drug abuse, and contraception).

Impact of Diabetes on the Elderly

Describe how diabetes may affect and be affected by the aging process and developmental tasks of later life.

- Recognize the impact of acute and chronic illnesses in diabetes management.
- Recognize intensive therapy should be available for older persons with diabetes.

Describe strategies for compensating for physical effects of aging on diabetes self-care practices.

- Recognize safety issues specific to the older adult with diabetes.

Diabetes Mellitus and Pregnancy

State the rationale for screening for diabetes in all pregnancies.

- Describe the effect of gestational diabetes on the outcome of pregnancy.

Describe the effect of preexisting diabetes on the outcome of pregnancy.

- State the importance of counseling and blood glucose control for women with diabetes prior to pregnancy.
- Describe the effects of pregnancy on long-term complications of diabetes.

Explain the importance of blood glucose control during pregnancy.

Cultural Issues

Discuss the impact of cultural background, beliefs, and environment on adaptation for diabetes.

Discuss the impact of culture on self-care practices.

Discuss economic issues related to diabetes care.

Components of Diabetes Patient Education

Recognize that diabetes education is necessary for patients to make informed choices regarding diabetes care.

- Tailor diabetes education to the needs and appropriateness of the learning setting.
- Individualize diabetes education to the appropriateness of the learning setting.
- Perform an educational needs assessment.
- Establish learning goals with the patient.
- Develop and implement an individualized education plan.
- Establish a follow-up educational plan.
- Document the teaching/learning process.

Discuss appropriate methods for teaching various aspects of diabetes self-care.

- Describe the rationale for the different levels of content within the teaching plan.
- Use appropriate and current teaching materials (pamphlets, booklets, films).
- Include family/significant others in teaching as appropriate.
- Recognize the importance of continuing diabetes education.

Understand the importance of regular medical/health care for persons with diabetes.

- Refer patient to other services as needed (social service, sexual counseling, home health care, etc.).
- Provide information about appropriate community services/resources.
- State the importance of referral to appropriate specialty medical care and educational services.
- Recognize the value of team approach to diabetes care.
- Describe community and national resources for persons with diabetes.

Patient Adherence

Respect the right of the patient to choose therapeutic goals and care options related to diabetes.

- Discuss the concepts of motivation, knowledge of self-care, health beliefs, quality of life, locus of control, and social support on adherence with prescribed regimens.
- Recognize that poor metabolic control is not necessarily related to nonadherence to the therapeutic regimen.
- State that adherence to one aspect of the regimen does not necessarily predict adherence to all aspects of the regimen.

Recognize positive and negative influences to adherence in the therapeutic regimen for diabetes.

- Discuss the value of a therapeutic alliance with the person who has diabetes.
- Describe situations where adherence may be difficult and generate replacement prevention strategies.

Research

Discuss the current trends of research in diabetes.

- Discuss the outcomes associated with the Diabetes Control and Complications Trial (and the United Kingdom Prospective Diabetes Study).
- Describe the implications of these outcomes for nursing.

Source: American Diabetes Association. *Diabetes Spectrum*. Alexandria, VA; 1993. Reprinted with permission.