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Rehab experts discuss psychosocial, neuropsychological issues in rehab

Train staff to handle difficult patients

Therapists, nurses, and others who work with rehabilitation patients sometimes need to give as much consideration to the patient's psychosocial and neuropsychological problems as they do to the physical issues, particularly in the case of patients who've suffered a traumatic brain injury (TBI), experts advise.

"When we talk about psychosocial rehab issues, we're really talking about a balance between issues that confront individuals and social and environmental issues that contribute to disability," says **Kurt L. Johnson**, PhD, associate professor and head of the division of rehabilitation counseling and department of rehabilitation medicine at the University of Washington, School of Medicine in Seattle. Johnson also is the director of the University of Washington Center for Technology and Disability Studies.

"So when we're working with patients, it's easy to look at the changes in physical function, measuring changes as people progress," he notes. "It's difficult to know what impact that really has on someone's day to day life when they get out of rehab care."

Likewise, it's challenging for staff to modify their treatment approach based on a patient's cognitive deficits, says **Mary Pepping**, PhD, associate professor and neuropsychologist and clinical director of the outpatient neuro-rehabilitation program at the University of Washington.

"All of the members of the team, whether they are occupational therapists, physical therapists, speech therapists, vocational rehabilitation, or respiratory therapists, have to know what are the two or three primary deficits in thinking and behavior this person has," she explains. "Know where a person does well because you need to draw upon those strengths to help the patient compensate."

For example, suppose a patient has difficulty with complex attention and memory retrieval skills. Therapists who understand these deficits

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may want to move that patient to a quieter part of the gym before beginning therapy, or they may want to schedule the patient at times when the gym wouldn't be so busy, Pepping says.

Another strategy would be to have a small white board with the steps listed so the patient could see this and refer to it as he or she goes through exercise steps, she adds.

"This is so the patient doesn't have to remember 10 or 12 repetitions," Pepping explains. "Cueing the patient makes it easier for the person to stay on track and remember what he's doing." Also, therapists need to check in with these patients more often and repeatedly say, "Tell me what I just said to you," she advises.

"Keep instructions to two or three things at one time," Pepping says. "Don't overwhelm the patient with instructions; keep them short and sweet and straightforward."

Johnson and Pepping also offer these suggestions for dealing with patients' psychosocial issues and cognitive deficits:

• **Consider patient's psychosocial barriers.**

Rehabilitation staff need to look at patients' experiences from an insider perspective, considering the barriers patients will experience in their daily lives, Johnson says.

"An example of social barriers, and we see this among health care workers all the time, is a presumption that somehow the person's disability is the salient or defining characteristic of who they are," he explains. "So the disability becomes the most important characteristic, and people with disabilities are presumed to have more in common with each other than they do with people who don't have disabilities."

In a rehab setting, this attitude is reflected in how staff talk about patients, such as calling patients quads or paras or "those guys with TBI," Johnson notes. "By doing that, we lose the opportunity to understand more clearly who the individual is.

"We also see this in everyday life when someone talking to a person who has a vision impairment speaks loudly or uses expanded speech," he adds. "I have traveled extensively with a colleague who uses a power chair, and when we go out to dinner, often the server — without thinking about it — would ask me what she wanted for dinner."

Another colleague of Johnson's is blind and a grants writer. She enjoyed getting a cup of latte on her way to work, but she had to stop this habit because as she'd wait at the bus stop, people would toss coins into her latte cup, Johnson says. "Those attitudes are never malevolent, just misinformed. But they can be destructive over the long run."

Employ affirmations

• **Keep messages positive and affirming.**

"Rehab has to be focused on what's wrong to help people get back on their feet," Pepping points out. "But that's very demoralizing."

She emphasizes that it's important for rehab staff to deliver information in such a way that a patient is reminded of his or her skills and assets and whatever it is that makes that person proud.

"The person who has been hurt usually compares himself to what he was before the injury," Pepping adds. "The therapist takes him from the

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point of the devastating accident to where the person is much better."

The idea is to help patients find and accept a middle ground where they can maintain hope and pride in their accomplishments, she explains. "Everybody needs a breather from that kind of intense focus on what's wrong."

• Be aware of patients' poor control and lack of awareness.

Rehab therapists face several hurdles in coping with patients who have cognitive impairments as a result of their illness or injury. Among these is a lack of awareness on the part of the patient about the actual injuries, Pepping explains.

"If the brain is hurt, the person's ability to size up damage is an issue; because if they're not aware of the problem, it's difficult to work on it," she says.

Another hurdle is the inability to accept the cognitive problem. "If they can't accept that there's a problem and that they need help, then they may not be very interested in treatment," Pepping adds.

The last major hurdle involves emotional and behavioral control, which, in some patients, can be so poor it's difficult for therapists to work with them, she explains.

"If they can't control themselves well enough not to hurt staff, then they won't be in rehab, but other patients have the potential of rage reactions when they encounter a deficit," Pepping adds. "They may cry or run from the room or yell, and that's a tough person to manage; and that requires a lot of individual therapy, group therapy, and behavioral plans, and taking it very slowly."

Those types of patients are on the brink of being overwhelmed all the time, she adds.

• Assist patients with advocacy skills.

"In my experience, the rehab staff are more likely to treat people as whole people, and I think, generally, they are pretty good advocates for their patients," Johnson says. "But the trick, I think, is to think not only about physical rehabilitation, but also about what kinds of psychological and what kinds of advocacy skills patients will need once they are out of the hospital."

For example, here are some questions therapists might consider:

— How well-versed are the patient's family members in what their legal rights are?

— How much do they know about some of the huge barriers they'll encounter in the health care benefits systems and elsewhere?

— How much continuity is there between inpatient and outpatient care and life in the community for people with disabilities?

"One of our patients was talking to our staff not too long ago, and she said that the key issue is to use people-first language," Johnson says. "Among disability advocates, the idea is people-first language reminds you to consider the individual, and it's important not just when talking to the patient, but also when talking with each other because the feeling is those shorthand terms, like 'quad,' end up stereotyping people unintentionally."

Really listening

• Assign therapists according to patients' needs.

It's best to assign therapists to patients with psychosocial difficulties according to the patient's particular needs, Pepping says.

It may not always be an easy strategy with regard to scheduling, but it makes a lot of sense from a psychosocial standpoint. For example, a patient who tends to view women as a source of nurturing and support might be assigned a woman therapist, she explains.

"Other patients might find companionship with male therapists is more comfortable, so assign them male therapists," Pepping says. "It's a matter of who's going to be most compatible with that patient."

Another strategy is to have a psychologist or physician participate in a physical therapy session to give the patient additional support, she says.

• Listen without assumptions.

"The idea is to learn to listen carefully and from different perspectives because we have to assume that a lot of expertise about disability resides with the person who's disabled," says Johnson. "Early on in rehab, we're teaching them to become experts in their own disability, and we want to reinforce that expertise and listen to their experience and trust the validity of their experience."

It's difficult for rehab staff to trust patients' understanding of their experiences when patients have communication impairments or brain injuries, he notes.

Likewise, patients themselves and their families have trouble coping without assumptions because they perceive the patient has changed, Johnson explains.

"Especially when there are communication challenges, you have to slow down, and communication may take more time," he says. "In medical settings, we're all under increasing pressure to generate billing, and so it may be hard to slow down, but give the person a chance to explore his feelings about what is going on and to understand them." ■

More education about cardiac rehab needed

Black and poor women referred less often

Despite ample evidence that cardiac rehabilitation services provide health benefits to people who have suffered from a heart attack or other cardiac trouble, clinicians still do not make automatic referrals to cardiac rehab programs, a recent study shows.

Several medical organizations have published guidelines recommending that anyone who has had a myocardial infarction be referred to cardiac rehabilitation, says **Jerilyn K. Allen**, RN, ScD, FAAN, an associate dean for research and a professor at the Johns Hopkins University School of Nursing in Baltimore.

"Patients who have undergone revascularization and, in particular, coronary artery bypass surgery also qualify for cardiac rehab in terms of guidelines," she says. "And people who've had angioplasty or coronary interventions also should be referred."

However, research by Allen and colleagues shows that too few women who suffer from heart attacks are referred to cardiac rehabilitation services.

Specifically, the study found the rate of referral to outpatient cardiac rehabilitation was significantly lower for African American women than for white women, and women with annual incomes of less than $20,000 per year were less likely to be referred to such services, even if they had access to insurance that would cover the services.[1]

African American women were 58% less likely to enroll in cardiac rehab services than white women, and when the results were controlled for income, there was borderline significance, Allen notes.

"It's always dangerous to conjecture, but we do know there are health disparities out there based on socioeconomic status, as well as ethnicity, and this is another potential piece of evidence that there may be some bias in terms of referral based, really, on socioeconomic status," she says.

"Referral should not be based on people's ability to pay because a majority of the women surveyed were covered under Medicare, which covers cardiac rehab," Allen notes.

Of 253 women surveyed, only 19% reported receiving a referral to outpatient cardiac rehabilitation, and more than half the women said they had no knowledge of cardiac rehabilitation, the survey found.

Women who had incomes of less than $20,000 a year were 66% less likely to be referred to cardiac rehab, Allen explains.

"A high percentage of the women surveyed said they were very interested in rehab and stated cardiac rehabilitation was something they would have liked to have taken advantage of," she says.

Although the study relied on the memories and reporting of patients, it's unlikely patients would say they had not received cardiac referrals if they had, or if they had forgotten about a referral, then that would mean it wasn't communicated in an effective way, Allen notes.

Increase outreach efforts

The study highlights the need for rehabilitation facilities to increase outreach and educational efforts regarding cardiac rehab services.

"Frequently, what happens is a cardiac surgeon may not see a rehab referral as within his scope of practice, that it's not his responsibility to recommend cardiac rehab or to help a patient with follow-up through cardiac rehab," Allen says.

"The primary care provider might see it as the cardiologist's responsibility, so it could be that people may think rehab's important, but see it as within someone else's purview to do the referring and discussion; and as a result, it gets lost," she points out.

The solution would be an automatic referral system in which cardiac patients leave the hospital with some type of outpatient cardiac rehabilitation referral, Allen suggests.

"For example, there are discharge prescriptions," she says. "When a patient is discharged it's part of discharge planning, and so rehab would have to be integrated into discharge planning and not just into patient education."

When a physician writes a rehab referral order,

it sends a strong message to patients that they think this is important, she adds.

The rehab referral bias that meant poor and, perhaps, black women received cardiac rehab referrals less frequently than white and affluent women is difficult to explain, although Allen and co-investigators have been studying potential explanations for these findings.

"We did some focus groups with providers, cardiologists, primary care physicians, and cardiac surgeons to determine their perspective on why this is happening," she says. "We received some hints that relate to actual biases and some concerns about whose responsibility it is and who should be doing it."

Not conscious biases

The biases did not appear to be conscious biases and not racism, Allen points out.

"We're talking about biases in terms of saying, 'Well, they're not going to go to rehab anyway,' and that kind of thing," she notes. "And that has evolved from many years of getting negative feedback about people not staying in cardiac rehab or not ever going."

Also, physicians expressed some concerns about the benefits of cardiac rehab and whether it really is necessary when people could exercise on their own at home, Allen adds.

"I think it's going to take more than just education, but maybe in the form of providing feedback to physicians about their patients and how their patients have gone to cardiac rehab and how well they've done, and so forth and so on," she says.

"Maybe that's the way to change an attitude, by making it more real as opposed to quoting guidelines and studies," Allen continues.

The rehab industry would make faster progress in marketing cardiac rehab services to physicians if it would get patients to provide positive reports to doctors, she says.

"Patients are wonderful about giving messages back to physicians and changing their attitudes," Allen notes. "So activate the patient to motivate the physician to use rehab, and it could work in this situation to change attitudes."

Reference

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ADA 15 years later: Has there been progress?

Experts discuss highs and lows

[Editor's note: Rehab Continuum Report *asked several experts on the topic of the Americans with Disabilities Act (ADA) to discuss the legislation and its impact on rehab and people living with disabilities since the act was signed into law in 1990. In this question-and-answer report, the experts discussing the ADA are* ***Shelley Kaplan****, MS, CCC, a research associate and principal investigator at the Southeast Disability and Business Technical Assistance Center (DBTAC) in Atlanta;* ***Curtis Edmonds****, JD, an accessible information technology specialist with Southeast DBTAC; and* ***Pamela Williamson****, an assistant project director with Southeast DBTAC.]*

Question: Next year marks the 15th year of ADA. During this time, how much has the ADA changed the way Americans perceive and accommodate people with disabilities, and do you have some examples of this change?

Kaplan: "This is the $64 million question. We have the National Organization on Disability's Harris Surveys, done in 1986, 1994, 1998, and 2000; and it just released the latest of 2004 and concludes that progress is too slow and the gaps are still too large. But there have been some changes.

"The unemployment rate still is pretty low: More than one-third of people ages 18 to 64 with disabilities, compared to two-thirds of people without disabilities, have full-time employment.

"Although about one in five people with disabilities who are employed still encounter job discrimination; it has decreased over the past four years, somewhat. The types of job discrimination have changed dramatically. We see more accessible parking spaces, more curb ramps being built. We've seen more audible pedestrian signals on the street. We've seen a lot of thought going into the new stadium-style seating in theaters.

"That's still a contentious issue: Even though it improves the viewing angles for everybody, stadium-style seating still congregates people with disabilities either in the front or back, so it doesn't give them the same comfort as the rest of us. The Department of Justice continues to fight this battle."

Williamson: "One of the positive changes that we've seen is the fact that the Department of Justice has taken on a program called Project Civic Access, which has really highlighted the need for cities and towns to look at their overall disability policies as well as physical access. So this is addressing the many arenas across the nation, and they have come up with model settlement agreements.

"It has really helped to increase awareness as well as access in many areas.

"One city that has really taken this to heart is Nashville, TN — Davidson County. It self-reported as being noncompliant to the federal government, and really embraced the whole concept of making the whole city and county as accessible as possible in every area.

"It's working closely with the Department of Justice to make sure it is fully compliant with the Americans with Disabilities Act in policies and procedures, as well as in access to buildings and everything. Information is available on-line at the Department of Justice web site at www.usdoj.gov/crt/ada/civicac.htm."

Question: Despite the progress, some court rulings in the past decade would appear to limit the ADA's reach. Could you please elaborate on some of the more important rulings and how these impact the rights exercised by people with disabilities?

Edmonds: "There have been 18 lawsuits that have gone all the way to the Supreme Court. There have been over 1,000 decisions by lower courts, but the most important decisions and the ones that have a national range are done at the Supreme Court. A lot of these decisions deal with the definition of disability. In other words, which individuals are actually covered by the ADA?

"The ADA is different from other civil rights laws. Other civil rights laws cover the entire population, the ADA only covers individuals with disabilities, although it can cover individuals who have an association with someone with a disability, as well.

"The definition of disability in the ADA is an individual who has an impairment that results in substantial limitation in a major life activity, and that also includes individuals who are regarded as having such an impairment or individuals who have a record of such impairment.

"One example of a major Supreme Court case in this area is *Sutton v. United Airlines*. *Sutton* involved twin sisters who wanted to work as airline pilots for United Airlines. Both of the sisters were legally blind. However, they both wore eyeglasses; and with their eyeglasses, they had corrected vision that was good enough to pilot an airplane.

"United Airlines said that because their uncorrected vision was not good enough to pilot a plane that they would not employ them as airline pilots. The Supreme Court determined that even those two individuals were legally blind they did not meet the ADA definition of disability. They determined that what you had to do is look at individuals in their mitigated state.

"If you have an impairment and an impairment can be anything — everyone in their lives has some sort of impairment. It's any disorder or disease or problem with a bodily system. But every impairment is not a disability, and if you have an impairment, you can take steps to mitigate that impairment. If you have poor eyesight, you can wear eyeglasses; if you have hearing loss, you can wear a hearing aid. All of these things are called mitigating measures because they lessen the impact of that impairment, and in many cases, they may keep it from becoming a disability.

"The regulations as they were originally written by the Equal Employment Opportunity Commission said that you look at people disregarding any mitigating measures, in what is called their unmitigated state. So you'd look at these two plaintiffs as though they never had eyeglasses, and then clearly they would have a disability because they wouldn't be able to see. They'd have an impairment; and there would be potential limitation on their ability to see, and it would impact a major life activity.

"The Supreme Court said, 'That's not appropriate, and that's not consistent with how we interpret the ADA. You have to look at people as they are and make an individualized determination based on the actual limitations of actual people. . . .' They determined that these two pilots did not have a substantial limitation in their ability to see when they were wearing their glasses, and that has a lot of impact for a lot of people, including people with mental illness who take medication; people with diabetes who take insulin; people with epilepsy who have all the different medications or different devices being used to control epilepsy; [and] people with learning disabilities who have developed different strategies and ways for them to be able to read

and understand information. And all of these people with these various types of impairments might have been covered by the ADA at one time or another and might not be covered if they go into a court because the court is going to have to look very closely at whether or not they have a disability and whether Congress intended for those individuals to receive civil rights protection because of their impairment."

Question: Rehabilitation center staff often work with state vocational rehab specialists in finding employment and work accommodations for people who have been disabled due to recent accidents or health problems. What do you find are some of their biggest challenges in convincing employers to make accommodations that are not directly spelled out in the ADA?

Kaplan: "It's not really that it's a challenge; it's that there's a lot of ignorance and attitudinal barriers that continue to be the biggest barrier. You can put all the legislation you want on the books, but you can't legislate attitude. No. 1, we have ignorance that continues to prevail.

"Despite research to the contrary, employers still think people with disabilities are not reliable, skillful workers. They think they'll be absent a lot because of medical treatment. They still feel that to accommodate a person with a disability will cost a lot, and they are ignorant about where the resources are in terms of who could help them figure out what the accommodation might be. Unfortunately, the media continues to contribute to this misinformation, and it's very frustrating.

"Even when we talk with the media, which we do quite a bit, we're careful with how we phrase things, but then some of our statements are taken out of context, and it gives a whole different impression.

"Businesses are also still ignorant about the tax credits that are available to help them with barrier removal, hiring of qualified persons with disabilities, and a lot of them still have fear about disability. It's the largest growing minority group, and it's the only minority group that any one of us can become a member of at any time; and I think that is instilling a lot of fear, unfortunately."

Question: Wasn't there a case involving carpal tunnel syndrome, which is a big workplace issue, and some rehab facilities have therapists who can help people with this problem? But what was the court ruling about carpal tunnel syndrome?

Edmonds: "The case was involving Toyota, and what happened was there was a lot of confusion over what it meant to have a substantial limitation in a major life activity of performing manual tasks. It's very technical, and basically, the Supreme Court undid a lot of what previous courts had done on this issue. But if you read the opinion and are knowledgeable, it's very clear what the court was trying to do.

"They were trying to clear up the way that this particular major life activity was treated. Everyone knows what it means to do walking and talking and seeing and hearing. Performing manual tasks is a little bit different because people do so many things. So this case gets into the media, and it's interpreted that carpal tunnel syndrome is not a disability; but that's not what happened.

"People in the media don't take the time on deadline to read everything in the Supreme Court decision and to get every little nuance out of it; it's just not possible. So there's a lot of media misinformation out there about carpal tunnel syndrome and the ADA.

"What the Supreme Court said is if you have carpal tunnel syndrome and there are things you cannot do with your hands, you have to show exactly what you can and cannot do; you have to enter that into evidence. What the plaintiff said in her deposition is that she could not work with power tools located above her shoulder level that vibrated. Well, that's not a substantial limitation because most people don't work in that environment with power tools that are over their heads. It has to be the kind of limitation that people have in the general population.

"So the court said that what you need to do is go back and show us what you can and cannot do with your hands in the day-to-day environment that everyone has to work with. And a lot of that involves brushing your teeth, brushing your hair, doing laundry, going grocery shopping; and you have to show what kind of problems you're having in a day-to-day environment. If the only thing she's limited in doing is working with large power tools then that's probably not going to be a disability.

"I think employers are going to continue to look at ergonomics and are going to continue to try to avoid carpal tunnel syndrome because they don't want that hit on their workers' comp budget. But when someone actually develops an injury that becomes a disability, they may have a hard time accommodating them based on this case. They may assume that the Supreme Court

said carpal tunnel syndrome is not a disability, and it just goes back to ignorance and fear."

Kaplan: "When the 2004 Harris survey looked at the different types of job discrimination and how it's changed over the years, one of the factors was being denied a workplace accommodation; and in 1998, when they measured that, they found that 22% of population of people with disabilities were denied a workplace accommodation. It really doubled to 40% in 2000, and in 2004, it dropped down to 21%. So there's been a significant improvement at least from 2000 in employers' understanding their requirements to provide a reasonable accommodation.

"Where difficulty persists is making information accessible to people with visual and hearing impairments. This whole requirement of effective communication, which to us seems to be the easiest one of all, appears to be among the more challenging and difficult. It's ignorance. People don't realize what's involved. You have to look at your application and how you advertise when you have jobs available; when you look at training material to modify these so they're accessible to people with disabilities, and it just becomes overwhelming."

Williamson: "The Program on Employment and Disability at Cornell University actually backed this up when they did a survey about six years ago. They said about half of their respondents lack familiarity with using such things as TTY or relay service and not being able to access sign language interpreters or not knowing how to access sign language interpreters or to put their materials in Braille or on disk or even thinking in that vein was part of the problem.

"People just didn't think to be familiar with it, and so they were looking for some guidance in how to do that.

"One of the things we found that is backed up by the Cornell group is that the disabilities not readily seen or what people are less familiar with are the ones where the accommodations are going to be the most difficult. A person with a head injury or a person with a learning disability or even people with hearing or learning impairments — those are the ones that people find the most difficult to accommodate because they feel like they don't have any resources for them. A person in a wheelchair is a disability that is readily identified.

"The other arena that also becomes sticky at times is people with psychiatric disabilities. That is a whole arena of individuals who often have many barriers in front of them and where the accommodations are least likely to happen because people don't understand mental health issues, and there's a stigma attached; and so many times the accommodations are seen in a very negative light.

"People with mental illness are among the most disenfranchised people in our country. We read so many articles about increase in workplace violence, and that fear seems to get in the way of providing accommodation for people with mental health issues. They link the two, although there's no research that suggests that people with mental illness who want to work have greater incidence of violence in the workplace. It's our own fear and stereotypes that get in the way."

Question: Do you feel that the ADA has accomplished much of what legislators intended when they passed the law in 1990, and why?

Kaplan: "The ADA is definitely a work in progress, and I think that's the nature of civil rights laws. It's not like you open a recipe book and say, 'This is the situation, and here's what we can do about it.' You have a general list of requirements, and then you have some parameters and defenses against those requirements. You have to look at the individual in a particular environment and determine what is the best option that will work that is reasonable.

"So we like to think of the ADA as a thinking person's law. The American public and business are saying, 'The government is overregulating us.' With the ADA as a piece of civil rights legislation, the onus was put back on business and states and local governments to say, 'Here are your obligations — you figure out the best way to maintain the integrity of your business or service while providing equitable access to people with disabilities. But then they say, 'The law is too vague; tell me what to do, and we'll do it.' So it's a thinking person's law, and it will take time.

"We have the Civil Rights Act of 1964 — and has that ended discrimination? No. So it's going

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to take a long time for everybody to understand it and to take it personally, and again, whenever we find someone who is a true advocate and doesn't have a visible disability, then if we dig deep enough, we'll find they have someone in their close circle who has sensitized them and made them aware." ■

Hallway talk can violate HIPAA privacy rule

Have you ever been walking through the hospital and overheard staff talking about patients? So have plenty of other people, according to new research that warns such overheard conversations can be a serious breach of patient confidentiality.

The research was conducted at Purdue University in West Lafayette, IN, by **Maria Brann**, assistant professor of communication studies at West Virginia University in Morgantown, and **Marifran Mattson**, associate professor of communication at Purdue. Their work shows patient privacy is breached when hospital employees talk about patient cases in public areas, such as the cafeteria, or with people outside of work.[1]

"The country has recently invested a tremendous amount of resources in the nation's largest set of federal privacy laws to prevent health care providers and institutions from divulging or selling patient information," Mattson says. "But we found that the daily conversations of physicians, nurses, hospital staff, and technicians can jeopardize the same kind of personal information. So not only is there a need for privacy laws, but also we see how challenging it is to maintain such laws in the simplest setting of people talking to each other."

Mattson says the research should be a warning to health care risk managers. She suggests they "seize the opportunities to teach privacy awareness and skills."

Frequent breaches of privacy

Mattson notes that hallway conversations can constitute breaches of HIPAA, which protects patients' medical information and limits access to that information.

Brann agrees, saying the research was prompted in part by what she observed while volunteering at a hospital as an undergraduate at Purdue.

"I noticed several instances when health care providers would discuss patients' information with other health care workers without being very discreet," she says. "Even though the study was conducted before the health insurance act was law, I don't think we would see a great difference in our results."

For the study, Brann only recorded observations in places that were accessible by hospital visitors, such as hallways, elevators, waiting rooms, and cafeterias. Fifty-one patients also were interviewed about medical privacy.

"Confidentiality breaches are occurring daily," she says. "While health care providers may not be malicious in their disclosures, they are still sharing patients' most personal information with unauthorized individuals, which has the potential to create problems for the patients."

Staff talk freely at home

Brann notes that disclosure of patient information can lead to identity theft, discrimination, or social stigma if a medical condition or patient identification information is inadvertently revealed.

The most common breach found in the study was in casual conversations between employees at workstations or in the cafeteria, where hospital personnel discussed health information about patients and co-workers.

Privacy also was violated when the public could overhear phone conversations with insurance companies or other medical consultants in which patients' phone numbers, addresses, and Social Security numbers were given. In one extreme example, a receptionist even spoke to insurance companies on speakerphone.

Health care providers sharing information with their family members also was a concern. Many of the subjects interviewed in this study acknowledged that their family members and friends who work in health care shared patient stories. Most of the subjects justified their loved ones' breaches of privacy as acceptable because their family members and friends were cautious about not revealing too many details.

"Even without identifying the patient by name, there is cause for concern, especially in a smaller community," Mattson says.

"The most serious consequence is that people will find out about loved ones' health problems from someone other than their health care provider," she notes. "Just as concerning is that if

patients realize their personal information is vulnerable, then they may be less likely to share important details with their physicians or nurses."

Brann and Mattson advise risk managers to remind health care staff about how easy it is to divulge patient information inadvertently.

Most breaches occur without the speakers even realizing they are being careless with patient information, so simply making people aware of the danger is a big part of solving the problem, Brann says.

"Health care providers need to pay attention to how they personally breach confidentiality laws, and patients need to bring breaches of privacy to the attention of their physician, nurse, medical assistant, or waiting room receptionist," she points out.

"When you overhear a phone conversation in a waiting room where the receptionist is repeating personal information, such as Social Security numbers, gently remind the person or supervisor that you are concerned," Brann adds.

Reference

1. Brann M, Mattson M. Toward a typology of confidentiality breaches in health care communication: An ethic of care analysis of provider practices and patient perceptions. *Health Commun* 2004; 16(2):231-251. ■

Class action lawsuits won't help uninsured

Not-for-profit hospitals under scrutiny

Mississippi attorney Richard Scruggs has targeted not-for-profit hospitals in his latest class action effort, accusing them of overcharging uninsured patients and using harassment to collect overdue bills.

But while the lawsuits are bringing fresh attention to a long-simmering problem, health policy experts and hospital officials say, they are not likely to help the uninsured.

"This lawsuit is totally baseless, without merit, and will serve only to line the pockets of the trial attorneys," says **Cheryl Iverson**, vice president for business development at DeKalb Medical Center in Decatur, GA, one of the hospitals named in the actions.

"They have only gone after the not-for-profits with the largest cash reserves. All of their allegations are completely contrary to our day-to-day business practices. We in no way use harsh collection practices, and we provide seven times the value of our tax exemption in uncompensated charity care," she explains.

Scruggs and several other attorneys, including some who also collaborated with him in his precedent-setting attack on the tobacco industry, filed class action suits June 16 in federal court in eight states against 13 not-for-profit hospital systems.

A week later, the same group filed five more class action suits in three more states and, on July 7, added six new lawsuits, bringing the total number of suits to 27 involving 15 states.

The lawsuits allege the systems have entered into explicit or implicit contracts with their communities to provide charity care in return for significant tax breaks.

The hospitals have breached these contracts, the suits contend, by charging uninsured patients premium prices while negotiating steep discounts with insurers, HMOs, and government payers such as Medicare and Medicaid. Some hospitals also use aggressive tactics to collect unpaid bills, pursuing liens on property and assessing interest on late payments.

All lawsuits also name the American Hospital Association (AHA) as a "conspirator" with the hospitals for providing "substantial advice to the defendant nonprofit hospitals on billing and collection practices as well as other aspects of hospital operations."

"The defendant nonprofit hospitals and the AHA know full well that the uninsured patients are being charged sticker-shock prices for hospital health care," the plaintiffs' attorneys stated in a press release accompanying the lawsuit filings.

The hospitals also engage in deceptive practices by overstating losses due to investments, and claiming uncompensated care as both charity care and bad debt, Scruggs and colleagues allege.

This is not the first time that attorneys have challenged the practice of charging uninsured patients higher rates than those covered by third-party payers, notes **Jay Wolfson**, DrPH, JD, professor of public health and medicine at the University of South Florida Health Sciences Center in Tampa.

Over the past decade, Wolfson has published research on the arguments for and against not-for-profit hospitals' tax-exempt status and on legal challenges to hospital charging structures and billing practices.

The lawsuits are drawing new attention to the

relatively hidden fact that hospital charges often are not reflective of the costs it requires to provide a needed service or procedure. Certain health care charges are inflated beyond what it costs to provide the actual service. Third-party payers also negotiate across-the-board discounts for their members. Thus, the charges to insured patients are lower, while the full charge assessed to uninsured patients, in many cases, is unrelated to the cost of care provided.

However, this is an issue that must be addressed on a societal level, Wolfson explains.

"Costs have not been relative to charges for nearly 20 years. And the concept of cost shifting has been endorsed by many state legislatures as essential to the sustenance of health care organizations. It has been adopted as public policy. It makes sense — particularly as it relates to expensive, essential, less intensely used services — such as burn and trauma and neonatal services," he adds.

Hospitals in a tight squeeze

The Scruggs lawsuits may lead some hospitals to change their charging structures, but this could actually hurt consumers in the long run, says **Timothy D. McBride**, PhD, professor of health management and policy at St. Louis University's School of Public Health.

During managed care's heyday, hospitals had little power to charge covered patients the same rate, he notes. Managed health plans covered so much of the market that they could force systems to accept slashed fees in return for remaining on preferred provider lists.

Now, however, with many plans facing financial crises of their own, hospitals might be able to force plans to pay more.

But this also could result in substantial increases in premiums, driving more employers to reduce or drop health coverage for the employees or induce employees to give up available coverage.

"The biggest factor driving the increase in the number of uninsured people, in recent years, has been decreases on the employer insurance side — employers are dropping coverage," McBride says.

Need More Information?

- **Cheryl Iverson**, DeKalb Medical Center, 2701 N. Decatur Road, Decatur, GA 30033.
- **Timothy McBride**, St. Louis University, School of Public Health, 3545 Lafayette Ave., St. Louis, MO 63104.
- **The Scruggs Law Firm, PA**, 708 Watts Ave., Pascagoula, MS 39567.
- **Jay Wolfson**, DrPH, JD, CPH 1126, Dept. of Environmental and Occupational Health, USF College of Public Health, Health Sciences Center, 13201 Bruce B. Downs Blvd., Tampa, FL 33612.

Squeezed by reductions in private payer and government-sponsored health insurance reimbursements, hospitals have borne the brunt of rapidly rising health care costs in this country. These lawsuits could induce hospitals to start pushing the burden back onto the taxpayers, he notes. "It is a vicious cycle."

Health care tends to be thought of by most people, as something that should be a purchasable commodity — until they need it, or someone they know needs it, and then they want it to be readily available and affordable, Wolfson says.

"Communities have to decide how they are going to address the needs of the uninsured," he explains.

"This means taking responsibility — something communities don't want to do, unless it is to fund a football stadium. We give lip service but little real credence to being our brothers' keepers. We are a crisis-oriented culture. We want instant gratification, not investment in the health and welfare and productivity of our communities."

While a societal debate over how to provide health care to the needy may be desperately needed, the problems will not be solved by this avalanche of lawsuits, Iverson adds, noting the hospital administration found out about the allegations when they were called by a reporter from *The Wall Street Journal*. The official legal notification came a week later.

DeKalb Medical Center's annual tax exemption amounts to about $4.5 million; however, the

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hospital provides almost $40 million in uncompensated care each year.

"The hospital has a well-established policy of providing charity care to patients who truly cannot afford to pay," she says.

"We work with everyone to find out whether they are eligible for any public assistance or government-sponsored health plans, then we look to see if they meet our guidelines for charity care. If they do, we write it off; they never even get a bill. If they don't, we offer to set up a payment plan and work with them to see how much of it they can pay," Iverson explains.

Even then, only 7% of those patients pay their bills, Iverson says; 93% do not pay at all, and the hospital absorbs this as bad debt.

Medicare requires, as a condition of the hospital's participation, that it make reasonable attempts to collect bad debt, she notes.

Iverson says she believes the hospital will be exonerated, but notes that it already has spent a great deal of money, time, and other resources preparing to defend themselves against the charges. "I don't know what the ultimate impact of the lawsuits will be nationwide," she adds. "But whatever the outcome, it will likely be millions of dollars that could have been spent on providing care that will instead be consumed by the legal system." ■

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NEWS BRIEF

CMS eases stance on rural rehab units

Rural residents who are Medicare beneficiaries and need inpatient rehabilitation services may be able to receive services in their own community hospitals thanks to new instructions issued recently by the Centers for Medicare & Medicaid Services (CMS).

The new CMS instructions, part of the Medicare Prescription Drug Improvement and Modernization Act of 2003, will allow critical access hospitals to set aside units of up to 10 beds each to be used exclusively for inpatient rehabilitation and psychiatric services.

The rehab and psychiatric units would be paid as if they were distinct parts of acute care hospitals and will have to meet the same standards as units in acute care hospitals. Medicare will reimburse for inpatient rehabilitation services in a critical care hospital-based rehab unit based on the 75% rule. Psychiatric services will be paid on a reasonable cost basis until a new prospective payment system for inpatient psychiatric services is introduced.

"We believe critical access hospitals have an important role to play in making it possible for patients to receive inpatient rehabilitation and psychiatric services in their communities," said **Mark B. McClellan**, MD, PhD, CMS administrator, in a statement released by CMS.

"[This change] is especially important for elderly beneficiaries in rural areas, whose support network of family and friends might otherwise find it difficult to visit," he noted.

Critical access hospitals are limited-service hospitals located in rural areas that receive cost-based reimbursement.

To be certified by Medicare as a critical access hospital, a facility must, among other requirements, be located in a county or equivalent unit of a local government in a rural area; be located more than a 35-mile drive from a hospital or another health care facility; or be certified by the state as being a necessary provider of health care services to residents in the area. ■