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Financial woes force Texas hospital to make 'heartbreaking' choices

Rationing uncompensated care only solution to worsening budget crisis

Frontline access management staff at the University of Texas Medical Branch (UTMB) in Galveston face excruciating tasks on a daily basis.

How do you tell a chronically ill single mother with outstanding debts to the hospital that she must work out a plan to repay what she owes before a new appointment can be made?

Or in another case, how do you tell a man with no insurance, but too much income to qualify for public assistance, that he must come up with a copay he feels he cannot afford in order to be seen?

This wasn't always the case.

For more than a century, the 110-year-old public hospital was the place that provided medical care to anyone, regardless of their ability to pay, no questions asked.

According to UTMB president **John Stobo**, MD, patients came to the hospital from 180 of the entire state's 254 counties, with even more people making 1,000-mile trips to get prescriptions filled at the hospital's pharmacy, which handed out six-month supplies to indigent patients free of charge.

All that began to change in 1998.

Cutbacks in federal and state support for the public hospital hit at the same time it was seeing its amount of unreimbursed care steadily rise and the cost of medicines and supplies double and triple.

By the end of the year, the hospital was reporting \$80 million in debt and faced with depleting its reserves just to keep the lights on.

At first, Stobo and other hospital leaders tried traditional forms of cost containment. They reduced the number of beds and cut almost 600 staff. They cut programs they felt they could do without and had not been performing well — the home health agency, hyperbaric oxygen treatments, and Life Flight went by the wayside.

But at the end of the day, Stobo says the cuts weren't nearly enough to close the gap.

"We realized that we had to look at the amount of uncompensated

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care that we provided," he says. "I resisted doing that for more than a year. But, ultimately, we had to look at triaging — or rationing — care."

A rational, consistent approach

Stobo convened a committee of hospital leaders — representatives from the clinics, different medical specialties, hospital admissions personnel, and

management — to develop a system that would ration the hospital's resources in a clear and consistent way.

The committee came up with a codified program, known as the Demand and Access Management Program (DAMP), which established rules for limiting uncompensated care.

They began by asking all new patients — not just those covered by insurance — to pay an \$80 copay unless they could meet the hospital's criteria for being indigent (less than \$2,800 per month for a family of four or 185% of the federal poverty level). Indigent patients qualify for a discounted copay of around \$30.

Children never are turned down, but adults who cannot make the copay are evaluated by a physician to determine whether their condition presents an immediate threat to their health. If not, they are turned away.

But the admissions personnel who perform the financial screenings also work with people to determine whether they may be eligible for federal or state programs that would help cover the cost of care, or whether they might be able to receive covered care in another setting, says **Barbara Thompson, MD**, chair of the department of family medicine and medical director of the hospital's clinics.

For example, when they started looking at where "unsponsored" patients were coming from, they discovered that 26% of patients presenting for care without an ability to pay for it were from Harris County, TX, the county that contains the city of Houston as well as the University of Texas Health Sciences Center, a Veterans Affairs hospital, several other hospitals, and most importantly, the Harris County Hospital District, another large publicly supported hospital.

"We discovered that some patients come here who really have another source for health care," Thompson recalls. "We did have a number of patients coming to us from Harris County that Harris County wanted to come to them, they receive funding to care for indigent patients in their county; but for whatever reason, they found it easier to get into our system."

A key focus of the screening process is to help determine what funding sources are available to help low-income patients of which the patients might not be aware.

"Of course, some patients don't have another source, and still don't qualify for assistance, and it is those people we need most to help. We need to make sure that we are taking care of the patients

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Editorial Questions

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that are most in need, especially since we have decreased resources now," Thompson says.

Patients who already have an established relationship with the hospital do not go through the financial screening process, but patients with outstanding obligations to the facility for a previous episode of care do have a bad-debt flag attached to their records that alerts personnel if they return to the facility.

"If they can make any kind of arrangement at all, sometimes just \$5 per month, then we go ahead and make the appointment," she notes. "But unfortunately, they do get that notification that we need to have something in place in order for us to see them again."

The hospital continued to make changes that affected all patients — moving to a specific drug formulary and ending some expensive and experimental treatments.

The pharmacy also stopped providing a six-month supply of medications to patients who could not pay — now, they only get 14 days' worth. The pharmacy has gone from losing \$12 million per year to just \$1 million.

EDs bear the brunt

Of course, the limits on access placed on nonurgent care means more patients are likely to end up in UTMB's and other hospitals' emergency departments (EDs) — often after their condition has become more severe, Thompson says.

"I think that is the real possibility," she continues. "What is going to result, all over the country, is more people going to emergency rooms and clogging emergency rooms, which impacts health care for everyone."

The financial crisis faced by UTMB is not unique, she notes. All over the country, public hospitals, particularly teaching hospitals, are seeing their subsidies for indigent care cut as states face budget shortfalls. At the same time, record numbers of people are without health insurance — 2.4 million more people lost coverage last year — and are turning to public hospitals for care.

For years, these hospitals have been the safety net for problems that society would like to ignore — the working poor who become ill and can't afford treatment. Now those hospitals, unable to absorb any more debt, are pushing the problems back.

The problem is particularly acute in Texas, currently facing a multibillion-dollar budget shortfall, with almost a quarter of its population uninsured.

As the health care system struggles under the weight of the mounting financial costs of providing care, the care provided to even wealthier, insured patients likely is to be affected, she notes.

With more patients crowding the UTMB ED last year, the hospital was forced, for the first time in its 110-year history, to go on ambulance diversion for a period.

Decisions based on values

What UTMB is doing with DAMP is acknowledging that rationing in health care inevitably occurs and attempting to establish policies that ration care consistently and openly across the board so that the procedures and methods can be scrutinized, says **Ronald A. Carson**, PhD, director of UTMB's Institute for Medical Humanities, a member of the institute's ethics consultation service.

"We ration all the time in this country, but most doctors feel better about it because they take care of the patient in front of them," he explains. "They have not been aware, and the public has not been aware — certainly the legislators don't seem to be aware — that there is a queue. That is one way we ration care, we take care of the people who can get into the system and then there are people who cannot get into the system because we run out of medicine or we run out of money or we run out of time."

The hospital's mission since its founding has been to serve the poor, and the hospital is committed to continuing to do so, but it has to find a way to serve those most in need, while staying solvent enough to remain in existence, he says.

Carson served on the initial committee that developed DAMP and continues to work with the medical leadership to evaluate how it is working and its impact on the facility and the people it serves.

"My emphasis is really more on patient care. Who is getting access? What kind of job we are doing taking care of people who don't have anywhere else to go?" Carson says.

Efforts at enrolling patients eligible for Medicaid, Medicare, and other programs, and efforts to redirect people to their local systems that can provide subsidized care, are two ways that UTMB seeks to reduce its burden and preserve its scarce resources for people who really need it, he says. "We are fully committed to remaining a safety net hospital, but what we are trying to do is ration access, in a morally responsible way, to our system."

SOURCE

- **John Stobo**, MD, President; **Barbara Thompson**, MD, Chair of the Department of Family Medicine; and **Ronald A. Carson**, PhD, Director, Institute for Medical Humanities, University of Texas Medical Branch, 301 University Boulevard, Galveston, TX 77555.

Even hospitals that don't consciously ration the care they provide are rationing care in a thousand different ways each day, he notes. Each time a physician must make a choice about which patient gets the one remaining ICU bed, or which patient should get an expensive test or medication the facility is trying to limit, rationing occurs.

"If you leave the policy decisions — or the decisions that are tantamount to policy decisions — to individuals at the bedside or consulting room, you can't be doing it fairly, because you just don't see the big picture," Carson says. "What ends up happening, even with the best intentions in the world, is that judgments that have nothing to do with medical indications get made — people get triaged and care gets managed on the basis of all kinds of things, social merit, and so on. I am not blaming anyone. It happens inevitably when you are thrust into that situation as a caregiver."

Although the staff at UTMB are getting more accustomed to working within the DAMP system, it still produces frustration and heartache, says Thompson.

Looking at the big picture may be the best way to provide the best care possible to the most number of people, but the individuals who do not receive needed care are real, and they stay with you.

Suggested reading

- Wysocki B. At one hospital, a stark solution for allocating care. *The Wall Street Journal*. Sept. 23, 2003. ■

New EMTALA may damage already weak safety net

ED physicians concerned over relaxed on-call rule

Hospitals struggling to survive while absorbing an increasing amount of uncompensated

health care are welcoming recent changes to federal patient-dumping legislation that clarify and limit the instances in which hospitals are required to provide care regardless of a patient's ability to pay.

But a portion of the new regulations may hurt access to specialty care for the nation's neediest patients, some experts say.

"EMTALA [Emergency Medical Treatment and Labor Act] is an incredibly important safeguard for all Americans," says **Wesley Fields**, MD, FACEP, president of the California chapter of the American College of Emergency Physicians (ACEP) and chair of the national organization's subcommittee on EMTALA regulations. "I think it is pretty interesting that the first form of health care to be protected under federal law is emergency care. Done well, it ensures that working people without insurance are going to be able to not just get medical screening and stabilization, but if they need hospitalization, they will be admitted to the hospital. But I think there is a big difference between EMTALA and the way health care safety nets should work within a market and within a region."

Passed by Congress in 1986, EMTALA required all hospitals that participate in Medicaid to provide medical screening examinations (MSEs) and stabilization to anyone presenting to the hospital and requesting assistance, regardless of that person's ability to pay for services.

The law was a response to instances of larger, affluent facilities engaging in patient dumping, turning away or transferring indigent patients with life-threatening medical emergencies and sending them to the nearest public hospital.

Under EMTALA, hospitals could be fined, sued, and lose their Medicare participation for:

- failing to provide a medical screening examination sufficient to rule out the presence of a medical emergency;
- failing to provide appropriate treatment to stabilize that patient prior to transferring the person to another site of care;
- asking for financial or payment information prior to performing an MSE;
- failing to maintain an appropriate roster of specialists on-call to treat emergencies.

Some later interpretations of the EMTALA protections further held that hospitals could be liable for failure to provide MSEs when patients presented to off-site urgent care centers owned by the hospital, or were transported to another facility in a hospital-owned ambulance.

Changes announced by the Centers for Medicare & Medicaid Services (CMS) in September and due to take effect Nov. 10 will limit hospitals' responsibility under the law. The new changes include:

- limiting the definition of hospital property where patients are entitled to emergency care. An off-campus site will be required to comply with EMTALA only if it is specifically licensed as an emergency department (ED), if the site is portrayed to the public as a place that provides emergency care, or if emergency services constituted at least one-third of all outpatient visits in the previous year;

- clarifying that EMTALA does not apply to doctors' offices, rural health clinics, nursing homes and other "nonhospital" entities;

- stipulating that EMTALA no longer applies to any person who is admitted as an inpatient;

- allowing hospitals more choice in arranging the federally mandated list of doctors who are on call to treat emergency room patients by allowing them to exempt senior medical staff members;

- removing requirements that hospitals have doctors on call 24 hours a day, seven days a week;

- allowing doctors on call to have simultaneous on-call duties at two or more hospitals and to schedule elective surgeries or other medical procedures while on call.

"Many of these changes are constructive," notes Fields. "The clarification that defines hospitals in a way that eliminates urgent care centers, and the point that EMTALA does not apply to a patient who is admitted to the hospital for another reason and then becomes unstable as a result of something that was not a result of the visit to the [ED], are both constructive measures."

On-call issue is tricky

But the relaxation of the requirements for maintaining a comprehensive panel of backup specialists has the potential to be devastating in some areas, Fields says.

The number of specialists willing to take call has reached such low proportions that many hospitals have to provide subsidies to reimburse specialists for the time they agree to be available.

A recent report from the General Accounting Office confirms that reductions in the number of specialists available to perform emergency surgeries and deliver newborns in EDs significantly has affected patient care in five states.

"Hospitals are increasingly being told by their own medical staff that EMTALA compliance is

really a hospital problem rather than a medical staff problem," Fields continues. "This is becoming a moral and ethical dilemma on the part of hospitals because, on the one hand, it is unfair to mandate panel participation for individual specialists; but the alternative that is increasingly seen in the marketplace is that hospitals will only get peak compliance or support from medical staff to the extent that they own the problem themselves in the form of providing different kinds of financial support to the specialists."

This hurts hospitals that serve low-income populations the most, he adds. Hospitals struggling to stay in the black may see cutting back on specialist backup for the ED as a good alternative.

"It becomes a matter of how much backup a facility can afford," he notes.

The intent of the change may have been to let hospitals in rural areas off the hook for providing an ophthalmologist or retinal specialist 24 hours a day, seven days a week, he adds. And to a casual observer, it may seem obvious that not all hospitals can, or even need to, provide such an intense level of specialization.

But because the change in EMTALA only requires hospitals to provide "reasonable" specialist coverage, there is a wide area open for interpretation.

"Even hospitals offering basic EMS response have to cover core areas of medical staff like medicine, general surgery, orthopedics, pediatrics, etc.," Fields says. "But you have to figure out what to do with those less frequent, but often very serious situations where you do need that very sophisticated specialist. I think that is our concern."

It's a real concern for providers of emergency medical services (EMS) because they may be left trying to determine which hospital is maintaining what types of specialists as backup for their ED, says **Robert Bass**, MD, FACEP, executive director of the Maryland Institute for EMS Systems, and chair of ACEP's EMS committee.

"From an EMS standpoint, we are concerned that we are going to have to start surveying emergency departments to determine who has complete coverage," he says. "Say we got a patient with an acute myocardial infarction; are we going to have to be concerned about which EDs have cardiologists that day and which don't?"

The new regulations also clarify that specialists can be on call at more than one facility. Particularly in rural hospitals with few available specialists, this could result in hospitals left with days with very little specialist coverage.

SOURCES

- **Wesley Fields**, MD, FACEP, President, American College of Emergency Physicians, California Chapter, 1010 11th St., Suite 310, Sacramento, CA 95814.
- **Robert Bass**, MD, FACEP, Executive Director, Maryland Institute for EMS Systems, 653 W. Pratt St. Baltimore, MD 21201-1536.

“The regs say that ‘reasonable’ coverage is required. If you’ve only got five doctors and they say that it is reasonable to take call once every two weeks or once a month, and they can argue it is not reasonable to be on call every five days or four, or even every three days, what can you do?” Bass points out.

It’s important to remember, Fields says, that EMTALA is a mandate on individual hospitals, and it’s not designed to be the safety net that some wish it to be.

“The real dilemma, especially with the backup issues, is that some of the specialty services you probably don’t need at every hospital, yet EMTALA is demanded of individual hospitals. It is not obvious to people, especially people in emergency medicine, how the local area will figure out a way to have hospitals that are still competing against each other for some services to comply with EMTALA in a way that provides safe, full-scope backup for patients.” ■

Mental retardation and reproductive freedom

Sterilization raises difficult ethical questions

Concerned that their loved ones’ mental capacities may not be able to keep up with their physical maturity, parents and guardians of adults and adolescents with mental retardation sometimes seek to have these people undergo medical sterilization procedures to prevent what they perceive as the potential burden of unanticipated parenthood.

Over the past decade, several surveys indicate that approximately half of all parents of mentally retarded children either have considered or would consider sterilization for their children.¹⁻³

“Fear of pregnancy, fear of sexual abuse, uncertainty about the efficacy of other birth control

methods, the desire to control or eliminate menstruation for either the purpose of hygiene or the child’s fear of the bleeding — these are frequently the reasons that parents seek these procedures,” says **Douglas S. Diekema**, MD, MPH, associate professor in the departments of pediatrics and medical history and ethics at the University of Washington in Seattle and Washington Children’s Hospital and Regional Medical Center. “These reasons are usually coupled with the belief that the child would never be capable of raising a child or sustaining a marriage.”

Diekema recently published a review of research into these procedures in the journal *Mental Retardation and Developmental Disabilities Research Reviews*.⁴

But the request for such procedures raises difficult ethical questions for health care providers.

It also recalls a particularly dark time in the nation’s past. In the late 19th and early 20th centuries, the eugenics movement strongly influenced legislation in many states, resulting in laws requiring the forcible sterilization of the poor, the mentally disabled, and people convicted of crimes.

Beginning in 1907, states began to pass laws that allowed, and in some cases required, the involuntary sterilization of those with developmental disabilities and mental retardation. Within 10 years, 17 states had passed sterilization laws.

In 1927, the Supreme Court’s decision in the *Carrie Buck (Buck v. Bell)* case cleared the way for states to forcibly sterilize those it deemed “unfit” for parenthood. By 1960, more than 60,000 men and women had been involuntarily sterilized in accordance with state laws.

It wasn’t until the end of World War II, when the world became aware of the atrocities committed by the Nazis in Germany, that involuntary sterilizations began to decrease in number and, in the 1960s, states began to repeal such laws. Some states took the additional step of requiring judicial review and other conditions before an individual deemed incompetent to make medical decisions could be sterilized.

Physicians are justifiably concerned that conducting such procedures at the behest of a person’s guardian, or, even at that person’s request, could start a slippery slope down the path of determining who should retain the capacity for reproductive freedom.

Legitimate reasons

Although sterilization procedures performed on people with mental disabilities have a troubled

past, most parents and guardians who pursue them today do so with the intent of helping improve the person's life, says **David Coulter**, MD, president-elect of American Association for Mental Retardation and a specialist in pediatric neurology at Children's Hospital of Boston.

"There are different reasons such procedures are pursued in men and in women," he notes. "But normally, it is sought for persons who require ongoing care and supervision — either by their guardians or in an institution — and not people who are capable of living independently or consenting to a sexual relationship."

Some women and girls may have difficulty coping with menstruation, for example; the pain and the bleeding may frighten them, and parents see the procedure as a means of ending their discomfort and improving the person's life, Coulter says. "It seems, to them, a simple solution — wouldn't it be better if they could just prevent it from occurring in the first place?"

There have been instances in which female residents of residential facilities assaulted by staff members then become pregnant, he notes. And some families see sterilization as a way to prevent the possibility of the additional burden of pregnancy should this occur.

"This is a difficult area to argue," Coulter says. "Of course, we can say that just should not happen, and we should always be able to protect people who are residents in these institutions. But, it does happen. And pregnancy or ending a pregnancy can be risky, invasive, and very traumatic for some individuals."

With men and boys, it may be that parents fear the results of a sexual relationship they believe the person is not able to understand. In some cases, they are trying to prevent sexually aggressive or inappropriate behavior.

Although, all of these efforts may be well intentioned, Coulter believes a desire for sterilization still indicates on some level that people are less inclined to consider the rights of persons with mental retardation on par with those of other people.

Though there may be some unique situations where sterilization is the optimal choice, he notes that most of the problems cited could be resolved through less invasive and permanent means.

For women, in particular, there are a number of contraceptive products that are available that would be nonpermanent, less invasive, and long acting, so that the person's life would not be disrupted.

If menstruation is a problem, it might be that the person's environment could be modified to

help them cope as opposed to eliminating menstruation altogether.

Health care providers who receive requests to perform these procedures should carefully consider all available options and consider the needs, wishes, and abilities of the individual people on a case-by-case basis.

"If at all, it should only be considered as a last resort," Coulter notes.

Balancing wishes and best interest

Under our current ethical principles, it is the health care providers' responsibility to ensure that any contraceptive measures be taken in the best interest of the mentally retarded person; and that decisions be based on the person's mental capacity and needs rather than the needs and wishes of people caring for or assuming responsibility for that person, Diekema adds.

When considering a request for a particular patient, not only is it important for providers to determine the person's overall level of competence and decision-making capacity, but also his or her specific capacity to understand and make decisions related to reproduction.

The fact that a person is unable to live independently and is not considered competent to assume total responsibility for decisions about health care, does not mean he or she necessarily is incapable of understanding and making decisions about reproductive issues.

Competence essentially means "the ability to perform a task," Diekema explains. Since a person may be competent to perform some tasks but not others, determinations of competence always must be judged for the particular decision under consideration.

"Persons who are deemed mentally retarded are a diverse group of individuals with a wide range of mental and social abilities who differ from 'normal' persons only in degree," he says.

To decide whether a person is competent to make decisions about reproductive issues, caregivers and health care providers should consider whether the person is able to understand the procedure in question, the available options — such as contraceptive therapy — and be able to deliberate about the risks and benefits of each.

The person's capacity to raise a child also must be considered, Diekema adds. Morally, he says, it makes little sense to talk about the right to reproduce without also talking about the responsibilities this would incur.

Some people with mental retardation do have the capacity to bear and raise children; and some people, though they would not be able to do so alone, might be able to do so with assistance in the future.

Diekema argues that a mentally retarded person who is competent to make decisions regarding reproductive matters should be able to choose sterilization if they desire it, but should not be subject to involuntary sterilization.

"I would further argue that involuntary sterilization ought not to be performed on persons who retain the ability to raise a child or to provide consent to marriage," he says. "Only if those three things are permanently absent should involuntary sterilization even be considered. Reversible forms of birth control could be used instead."

It's also essential — but difficult — to determine that a person lacking these capabilities now also will not have them in the future, Diekema emphasizes. "No sterilization procedure should be performed before puberty and no procedure should be performed until there exists absolute certainty that, over time, the person will not achieve these abilities."

Reasons for sterilization

Even if mentally retarded people lack the ability to comprehend or make decisions regarding their own welfare, it still should be the responsibility of people seeking a sterilization procedure to show why such a measure is in the person's best interests as opposed to alternatives, Diekema argues.

While permanent lack of capacity is a necessary condition for involuntary sterilization, that alone is not a justification, he explains.

"I would say the following must also be true: It must be urgently necessary; there should be clear and convincing evidence that the procedure is in the best interest of the person, and clear and convincing evidence that the best interests of the person cannot be served with less intrusive and permanent means," he says, also noting the widespread availability of numerous forms of long-term contraceptive methods available for women.

Serious psychological damage can result from decisions to sterilize a person against their wishes — even when those wishes cannot be considered competent, he adds.

However, it also may be true that such procedures offer people opportunities for freedom and

interaction in their communities that they might not be able to have otherwise, and this also should be taken into consideration.

Even people opposed to sterilization of mentally retarded persons often would go to great lengths to assure that individuals lacking the capacity to understand pregnancy or parenthood or to participate in child rearing not become pregnant, he notes. It is the responsibility of surrogate decision makers to protect people in their care from an unwanted pregnancy.

Effective contraceptive measures might afford a mentally retarded person more freedom and privacy to interact with other people. By enhancing opportunities and freedoms, contraception can provide significant benefit to mentally retarded individuals, just as it can for people deemed to be of "normal" intelligence, Diekema says.

This usually can be achieved with nonpermanent methods of contraception, but there may be some cases where sterilization would more represent a mentally retarded person's best interest, just as it might for other people.

It is vital that surrogate decision makers not confuse fertility with sexuality. Sterilization would not provide protection from sexual abuse or sexual activity. If restrictions on the activities of a person with mental retardation would continue to prevent the possibility of sexual abuse, then sterilization is not as easily justifiable.

"There need to be safeguards that ensure a fair and inclusive decision-making process — this would include a comprehensive evaluation by an independent professional and lay group regarding the medical, psychological, social, behavioral, and genetic data available on the patient, and to determine that the best interests of the mentally retarded person are aligned with the interests of the decision maker," he says. "The primary safeguard should be that the decision should be one that is reviewed by an independent third party, such as an ethics committee."

State laws permitting such practices also vary, Coulter says.

Some state laws prohibit such procedures without the person's valid consent, he adds. If the person is unable to give it, the procedure cannot be performed. In many other situations, a court order also is required.

Even if the opinion of an ethics committee is sought, the additional court hearing can provide an important venue for a deliberative process to ensure that the decision is in the best interests of the individual person, Coulter says.

SOURCES

- **David Coulter**, MD, President-elect of the American Association for Mental Retardation; Pediatric Neurology Specialist at Children's Hospital of Boston, 300 Longwood Ave., Boston, MA 02115.
- **Douglas S. Diekema**, MD, MPH, Associate Professor, Department of Pediatrics, Department of Medical History and Ethics, University of Washington and Washington Children's Hospital and Regional Medical Center, 4800 Sand Point Way N.E., Seattle, WA 98105.

"It should not be left up to the judgment of just the physician and the family," he says.

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For more information

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MD/patient communication styles often worlds apart

Effective discussions about risks are essential

Ask many physicians about informed consent and often you'll find they consider it a concept clear in ethics texts, but murky in practice. How many times have they labored to extensively explain the associated risks and benefits of a particular procedure or course of treatment to a

patient only to hear the reply, "Whatever you think is best, doc"?

Effective communication is essential to accurately conveying information about risk, which is essential to informed consent for medical treatments — which, in turn, is essential to shared decision making in health care.

The problem is that physicians and patients often figuratively are speaking different languages, says **John Paling**, PhD, research director of The Risk Communication Institute in Gainesville, FL.

"In every other field or industry we recognize that risk communication can be very confusing. In every field where risks have to be communicated to the public — the food and drink industry, chemical and nuclear industries — we have decided that only a limited number of people should be doing risk communication and they should have special training to do it," he notes. "But, when you look at health care, every clinician, every genetic counselor who faces a patient is doing risk communication, but very few have any training."

In his upcoming book, *Medics are from Mars, Patients are from Pluto*, Paling examines some common differences in the way physicians and patients communicate and offers advice for helping clinicians cross the divide. In an article in the September 2003 issue of the *British Medical Journal*, he also emphasizes how improved communication strategies can help patients get a truer picture of the risks they face.¹

First, it's important to realize that most patients will make decisions based on emotional perceptions more than on hard numerical data, and they need their caregivers to provide information in a way that takes this into account and helps them put information into perspective, he adds.

Surveys of patients and physicians have found that their definitions of what makes a physician a good doctor are vastly different.

Ask most physicians the traits they most admire in their peers and you will hear references to the person's level of education, where they've studied, how many articles they've published, etc. Ask patients the same question and most will respond that they value a physician's ability to convey information in an understandable way, the willingness to answer questions, and how comfortable they are talking with him or her, Paling says.

Information vs. data

Too often, physicians tend to give patients data about the risks of a certain procedure — numerical

odds about the chances for complications or for a poor outcome. But many people, and sometimes physicians themselves, have a difficult time placing the numbers into a context that enables them to make a decision.

But even when the data are put into context, they often are difficult for patients to comprehend. Many patients don't understand fractions and are put off by large numbers.

"We know very well that if I say you have a 97% chance of survival, you will probably have a procedure. If I told you there was a 3% chance you would die, you likely would not [have the procedure]."

Paling recommends using visual aids to convey information about the risks and benefits of a particular course of action. He has designed a form, known as a Paling Palette, which allows physicians to visually demonstrate fractions in a way that people can easily grasp.

The palette is a graph depicting figures that represent 1,000 people. In discussing the chances that a 39-year-old pregnant woman will have a child affected by Down's syndrome, the doctor can color in 12 of the figures to represent 1.2% (12 out of 1,000). In a separate color, however, the physician can also mark the four out of 1,000 women who have a miscarriage as a result of amniocentesis. In this manner, the patient can visualize the overall risk of both choices.

"The nice thing about the palettes is they show both the positive and the negative at the same time," Paling says. "You can see the 12 people who will be affected by this, but you also see the 988 who will not."

Discussions about whether a particular treatment is high or low risk often are not helpful because what one person perceives as an acceptable level of risk might not be acceptable to another, he says.

Some simple strategies often taught to risk communicators also can be helpful in communicating information about risks in the health care setting, Paling adds. For example:

- Don't use descriptive terms alone.
- Show the numbers of the likely odds of an event in a visual context, and use a consistent denominator. Don't use, for example, a risk of

one in 500 for one outcome and one in 1,000 for another. Some patients will actually perceive the risk of one in 1,000 as greater because of the larger number, Paling says.

- Use standardized vocabulary.
- Use absolute numbers as opposed to relative risks, such as "three times as many patients were cured with Approach A compared to Approach B" can be easily misinterpreted, Paling says.

Using visual tools also allows the physician and patient to take a more collaborative approach to making a decision, rather than having the physician present information and then wait for a response/decision from the patient, adds Paling.

"Using some simple shared thing, even just a piece of paper with some information on it, enables doctors to sit side by side with them and discuss the issue. That increases the patient's sense of the physician's caring and willingness to be a partner in the decision making," he says. "I call it a social lubricant."

Building a collaborative relationship with the patient is key to opening up effective lines of communication, agrees **Steve March**, executive director of the American Academy on Physician and Patient in St. Louis.

Formed almost 20 years ago, the academy sponsors research in physician-patient communication, advocates improved communications education for medical students, and offers continuing education in communications strategies for physicians.

"We have learned that the relationship between the physician and the patient is extremely important," March says. "And we know that the most effective approach is when the physician and patient work together in partnership; patients share information more effectively when they feel a connection."

When explaining a difficult diagnosis to a patient, doctors often get carried away using specialized terminology that may be familiar to them, but meaningless to patients, March adds. A more useful approach involves paying attention to the patients' existing knowledge, what the patient is feeling, what they believe, and what expectations they have, and presenting information that takes all of these factors into account.

COMING IN FUTURE MONTHS

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■ Emergency care and confidentiality for suicidal adolescents

■ Addressing disparities in health care

SOURCES

- **John Paling**, PhD, Research Director, The Risk Communication Institute, 5822 N.W. 91st Blvd. Gainesville, FL 32653.
- **Steve March**, Executive Director, American Academy on Physician and Patient, 1000 Executive Parkway, Suite 220, St. Louis, MO 63141.

"For example, if a person is shocked by hearing a diagnosis, their feelings become the immediate priority. Pressing forward to share more information at that moment can be pointless."

It also can be helpful to take a negotiating approach with the patient, he adds.

"Simply telling someone to do something can be ineffective," March explains. "Asking what they've already tried, asking if the plan sounds workable, and asking about what's important to them can be very effective in making a plan that the patient is invested in following."

Listening and building a relationship are keys, he adds. Physicians should use posture, eye contact, tone of voice, or gestures that help the other person feel at ease and more willing to share and discuss information about their condition.

Competence + caring = trust

A collaborative partnership can foster the trust necessary for patients to appropriately consider and participate in health care decisions, say both Paling and March.

In order for patients to trust their physicians, they first must believe that their doctor is caring and competent, Paling says.

"If you display competence without caring, you may have the patient's respect but not their trust," he says. "And of course if you care a lot, but don't display competence, that is not likely to inspire trust."

March once observed a physician's discussion with a patient who had a mental illness. Although regular medication had been controlling the woman's symptoms, it also caused some serious side effects, and she came to the doctor saying she no longer wanted to take the medication.

"Instead of immediately making the case for why she had to take the meds, the doctor simply asked why she wanted to discontinue," he says. "The patient talked about the side effects — she

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17. At the University of Texas Medical Branch in Galveston, the acronym for the hospitalwide policy on rationing is:
 - A. DAMP
 - B. TANF
 - C. ACLA
 - D. None of the above
18. According to our article, the provision in the new interpretation of EMTALA regulations that most concerns emergency medicine providers is:
 - A. The limit on what is considered hospital property.
 - B. Clarification applying to patients already admitted to a hospital.
 - C. The relaxation of standards for maintaining appropriate on-call specialists.
 - D. None of the above
19. According to our article, the sterilization of persons with mental retardation:
 - A. Never is never acceptable
 - B. Only should be considered as a last resort
 - C. Only should be considered after a thorough evaluation of the person's individual capabilities and wishes by an independent third party
 - D. B and C
 - E. None of the above
20. According to the article, what tools can be helpful in allowing physicians to communicate risk to patients?
 - A. Flash cards
 - B. Visual aids depicting numerical odds
 - C. Building blocks
 - D. None of the above

Answers: 17-A; 18-C; 19-D; 20-B.

wasn't treatment resistant or any such thing — she had a life to live and the side effects were interfering with it. The doctor went another step and surprised me by asking, 'What do you want to do?'"

After the patient explained that a different medication she had taken before didn't have the same side effects, the doctor was able to transition her back to that medication.

"In this instance, it made sense, and he agreed with the decision," March says. "These two had a relationship and were truly communicating. It was also fast. This makes a point about the time crunch that most physicians are facing and the ability to still take the time to build a relationship and listen. It pays off."

Reference

1. Paling J. Strategies to help patients understand risks. *BMJ* 2003; 327:745-748.

Additional information

- The American Academy of Physician and Patient: www.physicianpatient.org.
- The Risk Communication Institute: www.trci.info. ■