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Attorney General takes issue with physician-assisted suicide laws

Oregon is the center of a states' rights fight

As a federal appeals court considers whether to uphold U.S. Attorney General John Ashcroft's directive nullifying Oregon's state law allowing physician-assisted suicide, medical and legal experts are divided over whether Ashcroft's action could have more far-reaching consequences than its stated intent.

On May 7, the U.S. Ninth Circuit Court of Appeals heard arguments from attorneys for the state of Oregon and the U.S. Department of Justice over whether the federal government or individual states have the authority to regulate how controlled substances are used.

In November 2001, Ashcroft issued a directive stipulating that physicians who prescribe barbiturates with the intention of allowing a patient to end his or her life would be stripped of their federal prescription licenses. The directive, if enforced, would effectively nullify Oregon's Death with Dignity Act, which allows physicians to prescribe a lethal dose of drugs at the patient's documented request.

A federal judge ruled against Ashcroft in April 2002 contending that states, not the federal government, have the right to regulate medical practice. Attorneys for the federal government appealed the decision to the Ninth Circuit. A decision either way is expected to be appealed to the Supreme Court.

Some fear the directive, if upheld, will amount to a drastic reinterpretation of the powers the federal government has under the Controlled Substances Act.

"This is an act that was written in 1974 and created to prevent drug diversion. Its function is to keep drugs off the streets — a worthy cause — but it has little to do with what we are discussing," says **Susan Tolle, MD**, director of the Center for Ethics in Health Care at Oregon Health Sciences University in Portland. "The current case comes down to who has the authority to determine what a legitimate use of a particular controlled substance is. Is it the federal government or the states?"

The Controlled Substances Act allows physicians holding federally

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approved prescribing licenses permission to prescribe the specified substances for "legitimate medical purposes." The law does not specify which purposes are appropriate for which drugs, but Ashcroft contends that the law permits the federal government, using the discretion of the U.S. attorney general, to determine which uses of controlled substances are appropriate medical practice and which are not. Opponents argue that "legitimate medical purpose" is determined by the

states, which regulate medical practice within their borders by the authority of state medical boards.

"I think it also raises the question of whether you want them [the federal government] to make decisions about which other uses of medications are legitimate," Tolle adds. "I can think of many other uses that might be questioned."

Law's foes welcome challenge

Many physicians opposed to assisted suicide support Ashcroft's challenge and criticize Oregon's law for what they feel is an inappropriate association of suicide with the legitimate practice of medicine.

The major American medical professional organizations, including the American Medical Association, have stated repeatedly that physician-assisted suicide is fundamentally incompatible with the physician's role as healer and would pose serious societal risks, says **Kenneth Stevens, MD**, president of Physicians for Compassionate Care, one of the leading physician groups opposed to Oregon's Death with Dignity Act.

"Physician-assisted suicide is not a legitimate medical purpose," he says. "It represents a reversal of the proper role of physician as a healer, comforter, and consoler. By participating in assisted suicide, physicians are providing the direction and means for a patient's self-destruction."

In Stevens' view, use of any medication with the intent of causing a patient's death cannot be considered a legitimate use because the drug is not intended to treat a medical problem, but to end the patient's life.

Upholding Oregon's law will only allow other states to issue their own exceptions to the Controlled Substances Act, he argues.

Stevens disagrees with those who believe that upholding the directive would discourage aggressive use of medication to treat pain.

Surveys of patients choosing physician-assisted suicide in Oregon indicate that untreated pain is not a primary reason patients choose that option, he says. And the drugs prescribed and used in Oregon for assisted suicide have been barbiturates, which are sedatives, not medications, to treat pain.

"The attorney general has reassured the physicians of Oregon that the federal Drug Enforcement Administration considers the proper prescribing of pain medications with the purpose of pain control a legitimate medical practice, even if the pain medication may result in death," Stevens says.

However, physicians' perception that the

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federal government will closely scrutinize their use of controlled substances may lead many to be extremely conservative with their use — whether it is barbiturates or narcotics, says Tolle.

“I am not advocating and I have not been an advocate of the [assisted suicide] law,” she explains. “I don’t take a stand on whether Oregon’s law is a good or bad thing, and I don’t tell other states to do it or not do it. My interest is if you do things to change such laws, will other unintended consequences happen?”

The Center for Ethics in Health Care conducts a great deal of research into end-of-life care in Oregon, Tolle notes. An ongoing research program is devoted to monitoring how many people choose assisted suicide in Oregon, why they report choosing it, and the potential social, economic, and demographic factors that might affect their decision.

In addition, other researchers survey patients and families about other issues in end-of-life care — the frequency that advance directives are developed and implemented, how well care planning is performed, and how well terminal patients’ pain is managed during the final weeks of life.

In almost all areas, Oregon residents report more satisfaction with the care they receive compared to residents of other states, with the notable exception of one key area, Tolle says.

“We continue to see large numbers of people reporting severe, untreated pain and suffering at the end of life,” she says. **(See related story, right.)** “As many studies as we’ve done, and efforts we’ve made, I can find no proof that we have in any way improved the treatment of pain at the end of life.”

Statewide surveys of physicians and other health care providers indicate that the fear of being investigated for prescribing patterns is a large reason many do not aggressively prescribe medication, Tolle says. In Oregon, the only state that disciplines doctors for undertreatment of pain, that is a surprising finding, she adds.

In addition, she notes, the number of people choosing assisted suicide each year has remained relatively stable — approximately one per 1,000 deaths. Although the total number of assisted suicides last year was 17 higher than the year before, overall, the prevalence has remained the same.

Yet, no one is seeing a reduction in the number of people suffering at the end of life, Tolle says.

“That is a huge problem here and everywhere, and I don’t think you can find anyone to argue with me,” she adds. “It is not the overtreatment of pain that we are finding is a problem. It is not the lax and indiscriminate use of narcotics that we are finding. It is that we have large numbers of people experiencing severe pain and suffering at the end of life.” ■

Fear of investigation can hinder treatment

Survey finds pain management impacted

Despite all of its successes in improving care for patients facing the end of life, Oregon still has not made headway in treating pain and suffering, report researchers at Oregon Health Sciences University’s Center for Ethics in Healthcare.

Statewide, Oregon has made aggressive moves over the past decade to improve health care for its residents — particularly those facing serious or terminal illnesses.

And initiatives aimed at improving end-of-life care planning, access to hospice care, use of advance directives and living wills have all reported overwhelming success, says **Susan Tolle**, MD, the center’s director.

“But when people die, we are not seeing progress with treatment of pain,” she explains. “We are seeing progress on every other front, but not that one. Why is it that we can make so much headway, have giant coalitions of people who work on this statewide, in every hospice and nursing home, and elsewhere — we have all of our change agents in action — yet, in every study we’ve done, I can’t find any improvement in the management of pain.”

In 2000, the center published a study in the *Western Journal of Medicine* reporting that 54% of family members of dying patients in 1998 reported their loved one experienced moderate or severe pain in the last week of life.¹ In addition, the center

reported then that previously gathered data showed that complaints of pain levels of dying patients increased to 57% from 33% in late 1997.

Although researchers could not be certain why such a dramatic increase was reported, the feeling at the time was that there was both a greater awareness about pain treatment options by family members, coupled with an noticeable change in physician prescribing practices due to increased fears of regulatory sanctions, says Tolle.

"Late 1997 was a volatile time in Oregon's political and regulatory climate. Events such as the legalization of physician-assisted suicide and an extensive pre-ballot media campaign about end-of-life care were just a couple of things happening at the time," she notes.

Threats make no difference

In 1999, the Oregon state medical board became the first in the nation to discipline a physician for the undertreatment of pain and the state's physicians were put on alert that failure to adequately treat pain could endanger their medical licenses.

Since that time, the Center for Ethics in Health-care has gone back to take a second look at the number of patients and families reporting pain and suffering at the end of life, expecting to find improvement, says Tolle. They were wrong.

"We have some studies that are still in press, but what we are finding is that there is something different about the politics of changing end-of-life planning, and making that work, and changing the practice of pain management," she says.

"There appears to be something more vulnerable about pain management and we have certainly found it harder to bring about profound change."

The recent report by the nonprofit group Last Acts, *Means to a Better End: A Report on Dying in America Today*, featured a state-by-state analysis of how states scored on several key end-of-life care issues. When it came to pain management, Oregon ranked in the lower 50, Tolle adds.

"Some of that may be that we have taught people to better ask about and record information about levels of pain," she says. "But I have no information that we have seen reduced suffering, and we do studies all the time. We have a whole research program devoted to end-of-life care."

Surveys conducted by the center asked physicians about the reports of pain at the end of life, says Tolle.

The cause, according to those surveyed, was that "sometimes their colleagues were prescribing

less" medication than was necessary, she reports.

When asked why they would be prescribing less, the respondents indicated fear of investigation by the state medical board and fear of investigation by the Drug Enforcement Agency.

"What this says is that fearfulness and perception are real and they are a factor in the problem of inadequate treatment of pain and suffering in the dying," she says.

In most situations, it is not a case of a physician or nurse consciously deciding to undertreat a patient's pain, but with their overall tendency to be conservative rather than aggressive when treating pain, she says.

"We are not talking about people prescribing zero — we are talking about prescribing less than what is necessary to achieve relief," she notes. "The nurse calls and says, 'This patient is in terrible pain.' And they say, 'Give a little bit more,' instead of saying, 'Double the medication and call me back in 15 minutes.'"

The surveys also indicated that nurses were not being very aggressive in pursuing the physicians and aggressively treating the patient's pain when they could, Tolle says.

"If they have a range, 10-15 mg every two to four hours, are they giving 10 every four, instead of 15 every two?" she asks.

The responses of health care providers surveyed indicates that most of the reluctance is operating on a subliminal level with health care providers who are very risk averse and afraid of getting into trouble or being singled out.

"I think most providers want to avoid any scrutiny at all," Tolle notes. "If they hear about a physician who was investigated by the medical board and then cleared, after all the publicity is over and everything is said and done, it doesn't matter much to them that the charges were dropped. They don't want to face that at all," she notes. "If you are a new doctor and you just graduated from medical school with \$120,000 in loan debt, how likely are you to be willing to take that chance?"

The current climate, with the U.S. attorney general promising to scrutinize all prescribing of controlled substances by Oregon physicians, promises to put the state's doctors in even more of a squeeze, she says.

"We are concerned and trying to emphasize to Oregon's doctors that they should document more, not prescribe less," she says. "If you write in the chart, 'metastatic cancer, pain 10, morphine doubled,' can your intention be more clear?"

That's the message the center is sending, she says. But she fears her words will get lost in a cloud of misperception.

Reference

1. Tolle SW, Tilden VP, Hickman SE, et al. Family reports of pain in dying hospitalized patients: A structured telephone survey. *West J Med* 2000; 172(6):374-7. ■

When is it appropriate to nullify parental authority?

Legal action should be last resort

Pediatricians and other health care providers caring for children often run into conflict with the parents of their patients. As the Internet and other media outlets make medical information more accessible to the public, it seems more people are willing to question the judgment of the physicians assigned to their care.

But what happens when a parent's wishes are contrary to what the provider thinks is best for the child? Professional ethics dictate both a respect for the autonomy of the patient and the surrogate decision makers (the parents or guardians) and a duty to seek legal intervention if they do not act in the child's best interest.

Physicians treating children often must strike a delicate balance between respecting parental authority, and valid wishes that may run counter to their own and protecting the health of vulnerable children, say experts.

"It is not an uncommon occurrence. It is probably something that is occurring more commonly than in the past and probably more commonly than most people would imagine," says **Joseph R. Zanga, MD, FAAP**, head of the section on bioethics for the American Academy of Pediatrics and assistant dean for generalist programs at the Brody School of Medicine at East Carolina University in Greenville, NC. "Frequently, there are two directions: one, the parent who wants something done for the child that the pediatrician may not believe is in his or her best interest; two, is the refusal to do or the strong question about doing something the pediatrician thinks is in the best interest of the child."

A dispute in Michigan between parents of a critically ill 2-year-old girl and her physician

recently made national headlines after the girl's doctors sought legal action to force her parents to allow risky brain surgery needed to save her life, but carried a high risk of killing her or leaving her severely disabled.

Prosecutors in Pontiac, MI, recently dropped their quest to force the parents of Noshin Hoque to allow the surgery after doctors decided her condition had deteriorated to the point that surgery was unlikely to be of any benefit. Previously, two pediatric neurosurgeons told her parents that there was a 70% to 80% chance their daughter would either die or emerge with severe complications from the surgery to remove a walnut-sized brain tumor. Without the surgery, the child would definitely die.

Faced with those odds, her parents chose not to have the surgery, but to take the child instead to a homeopathic care provider in Canada in hopes of a cure.

The case is an extreme example of disputes that happen all the time in pediatric health care, says **Douglas Diekema, MD, MPH**, associate professor in pediatrics and emergency services and an adjunct professor of medical history and ethics at the University of Washington and Children's Hospital and Regional Medical Center in Seattle.

In teaching ethics students, Diekema frequently uses the illustration of an infant with a fever whom doctors fear may have meningitis. The physician wants to follow the standard course of ordering a spinal tap to rule out meningitis before proceeding. The parents don't want their small child undergoing a painful and traumatic procedure unless it is absolutely necessary.

"These parents often ask very good questions," he notes. "They sort of pull us away from what we consider the standard of care and this kind of broad consensus about how you should manage those babies."

The parents may ask about the likelihood that the cause of the fever is, indeed, meningitis and the answer, statistically, is about 1%, Diekema adds. They may feel that is too slim a chance to warrant such a procedure.

"The medical profession looks at this baby and says, 'Meningitis is a bad thing. Babies who get meningitis can suffer anything from hearing loss to brain damage to death.' A spinal tap, from our perspective, is a very safe procedure that is somewhat uncomfortable, but not horribly so," he says. "So, from a physician's perspective, it seems a no-brainer. Why take that chance?"

However, what the physician is really saying is that a 1% chance of meningitis justifies a spinal

tap, whereas the parents disagree — they think the procedure is very uncomfortable, and a 1% chance of a serious illness doesn't warrant it.

"That's why I like these kinds of illustrations because they expose what lies behind a lot of medical decisions, and that is that there are very few medical decisions that are purely objective, scientific decisions — they also entail some sort of value judgment," he explains.

Physicians must be able to acknowledge that their concept of the best interests of a patient entail some judgment based on their own personal values, he adds.

Advocate, don't force

A common conflict occurs when parents have qualms about immunizations or refuse to have their children immunized, says Zanga.

"That's a question of really sitting down with the parents and explaining the importance of having this done and the dangers, mostly nonlife-threatening issues, of not having it done," he says. "It is generally not something we would consider going to court about."

In conflicts that don't present a serious risk to the life or safety of the child, both Zanga and Diekema say physicians should not consider legal action to force parents to adhere to doctors' wishes, but instead counsel them as best they can and then adhere to their ultimate decision.

Another common example, cites Diekema, is when parents won't allow caregivers to administer a sedative to a child about to have sutures placed or another painful, but minor, procedure performed.

"The parents don't like the idea of this mind-altering drug going into their child, so they refuse it," he says. "I feel strongly that I should sedate a child to sew up his cut. I know the child is going to have an awful experience, and he's going to be kicking and screaming and remember it as traumatic; when with a little sedative, it would have been reasonably pleasant."

Beyond discussing his feelings with the child's parents, however, Diekema says he was unwilling to pursue the matter further.

"It does not meet the level of risk of serious harm," he explains. "I struggle a little more with the spinal tap issue because getting meningitis would be serious harm and there is not much risk associated with a spinal tap. But the risk is really too low to justify legal intervention — although you will probably get pediatricians

who disagree with that statement — who think that it is enough."

At the point that caregivers feel strongly a certain course is the best for the child, who may face significant, if not life-threatening consequences, physicians should try to explore other alternatives with parents — possible compromises that could make both sides happy.

"In the spinal tap cases, the alternative that usually suits the parents is admitting the child, putting them on antibiotics and treating them as if they had meningitis," he explains. "We would much rather give the spinal tap and then not have to treat the child [if it were negative] and not have them in the hospital for those extra days. But for most people, that is also a reasonable way to treat the child."

In another example, for parents concerned about the rumors that the MMR (measles, mumps, rubella) vaccine causes medical problems, Zanga may offer to give the shots, separately, after talking with the parent about his or her concerns.

"There are sometimes other ways of getting parents to do what is best for their child," he notes.

In some situations, however, physicians may feel that they in good conscience cannot accede to a parent's wishes, yet at the same time do not feel the situation warrants legal action. Immunization cases are sometimes an example of this, he notes.

"In that case, the club that some pediatricians use is saying, 'Mrs. Jones, I want to do what is best for your child, and I feel that what is best for your child is to have these immunizations. If we cannot agree on this, I am afraid there will be other situations in which we won't agree, and that puts me in a difficult position. If we cannot have a trusting relationship, perhaps it would be best to find another pediatrician who is comfortable with your position.'"

Rational not necessarily better

Diekema also cautions physicians against distinguishing between parents who make scientific or rational-seeming arguments and those who object to a recommended course of action for religious or cultural reasons.

"I don't think it should matter whether their decision is based on this sort of rational calculation of the risks vs. benefits, or it is a cultural thing or religious thing," he explains. "The latter two bother us more because we don't understand

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where they are coming from. My feeling is that when you are talking about intervening in the decision, it doesn't make sense to intervene in one case simply because the parents have a religious or cultural belief vs. this sort of rational calculation. If you interfere with the religious person, you have to interfere with the other person as well, given the same set of circumstances."

Health care professionals should focus on the situation and the possible consequences for the patient — the child — and leave judgments about the rationality of acceptability of the parents' argument out of it, he notes.

"We say we use the 'best interest' standard to help us decide. But what most people — doctors, lawyers, judges — really end up using is what I consider the harm principle," he continues. "Most ethicists argue that parents should not be able to make decisions that put their child at risk of serious harm. Short of that degree of harm or risk of harm, they should be allowed to make decisions even if we don't agree with them."

Diekema acknowledges that sometimes the potential for harm is great, no matter which choice is made — as in the Hoque case. In that situation, he contends, the decision should rest with the parents.

In a similar case in Delaware, physicians tried to force the parents of a child with cancer to allow him to undergo chemotherapy and radiation even though physicians estimated he had only a 40% chance of survival and the course of treatment would likely be very debilitating.

"It was a difficult situation with a high potential for a poor outcome. The parents, who happened to be Christian Scientists, said they didn't want to do it; they wanted palliative care," Diekema says. "The Delaware Supreme Court, wisely, I think, said they should be allowed to make that decision for their child, and they said it quite strongly and were quite critical of those who would challenge that notion." ■

Migrant farmworkers focus of new research

Hidden population doesn't get regular care

During a decade of providing health services to migrant farmworkers in eastern North Carolina, pediatrician **Andrea Weathers**, MD, DrPH, made some careful observations. In the clinic, she saw the same patients over and over again for health problems. But when she visited the camps and places where the workers lived, there were always other sick people needing treatment who did not come in for care.

In her role as a researcher and assistant professor in the department of maternal and child health at the University of North Carolina (UNC) School of Public Health, she wanted to find out why.

"I wanted to know whether the people who come in are the ones who really need care and find a way to come in, or whether — as I suspected — there was a large trove of unmet need in the community that is not able to access care for various reasons," Weathers tells *Medical Ethics Advisor*.

"When I would go out into the camps, there were always people who wanted care, but had not come in. You would go to a house to see one child, and there would be a mom in the same house behind a curtain with a 3-month-old baby with a fever. It happened all the time. I would be there for one reason, and then all of these people would show up, saying, 'Come look at my baby.'"

When she later became a public health researcher, she wanted to know if her experience was unique or represented a larger problem among migrant farmworkers. And if access problems exist, what causes them? But when she went looking for studies about factors influencing health care access among migrant farmworkers, she came up empty.

There was no systematic research into what factors influenced use of health services by the children of migrant workers. Are language barriers an issue? Does lack of insurance lead to nonuse of available services? What about access to financial aid and social service programs?

Weathers didn't know. And she found out, the public health community and health care providers didn't know either.

"If you look at the literature, there is a lot of anecdotal information — people with experiences similar to what I had seen," she explains. "But

really, I wanted to know if there was a systematic way to look at this as a population problem. When I looked, there was nothing available where anyone had looked for associations between different factors and use of health services, and then done a multivariable control to make sure there weren't other things leading to an association."

In the May issue of the journal *Pediatrics*, Weathers and colleagues at the UNC School of Public Health published the initial results of a systematic survey of health services use by children of migrant farmworkers in eastern North Carolina.¹

The paper is only the fourth article about the health of migrant farmworker children published by the journal since 1948 and the only one to examine the population's access to basic care services, fellow pediatrician **Steve Berman, MD**, notes in a commentary accompanying the study.² Berman is a professor in the department of pediatrics at the University of Colorado School of Medicine in Denver.

According to federal estimates, there are approximately 3 to 5 million migrant farmworkers in the United States, and health professionals treating these workers report a high prevalence of many acute and chronic medical conditions.³ In addition, farmworkers and their children continue to report exposures to high levels of toxins from pesticides and other chemicals used on the crops.^{4,5}

Researchers must overcome three challenges when attempting to study migrant farmworker children, he explains. One, establishing methods for defining and enrolling the eligible population is difficult when the population is mobile; 2) researchers must determine relevant measurable outcome measures; and 3) they must get community participation in the design and implementation of the study.

Weathers and colleagues' research is important not only for the information obtained, but also because it demonstrates that this population can be studied accurately, which may remove an obstacle to further research into ways to help these children, he wrote.

Sick kids getting care

To study the population, Weathers and the other researchers used a database from the North Carolina Migrant Education Program, a federally funded program to help states ensure education for children of migrant farmworkers.

Although funding for this program has been cut significantly in many states, it has remained well supported in North Carolina, Weathers notes. The

program has been in place for more than 20 years, and program staffers have good relationships with both the farmworkers and the farmers who employ them.

The program also routinely performs extensive canvases to locate migrant families and gather data on all children ages 3 years and older.

The database allowed Weathers and colleagues to look for both people accessing care in migrant clinics and to reach families not seen by the counties' health system.

Using their database, the UNC researchers performed a cross-sectional household survey using a multistage, partially random sampling approach to evaluate health services use by migrant farmworkers in the eastern part of the state.

They were able to gather data for 300 children about whether the children had used health services in the past three months, if their caretakers had access to financial aid available to families and to the services of an interpreter, if the children had health insurance, and other factors.

The results were somewhat surprising, Weathers says.

"I expected the only differences between those migrants using health services and those not using health services to be these sociodemographic factors — insurance coverage, access to an interpreter, whether the family was stable residentially — had a home for a stable period of time — those kinds of things," she recalls. "That was my original guess. I thought we had the same population, otherwise. But what we found was that factors differed across all three areas — there were different levels of need, differences in access to resources, and different sociodemographic factors, which was interesting."

What she found, however, was that the parents obtaining health services for their children reported the children as being in "less than good health" on the survey, while the children not accessing care were largely reported to be in "good health" by their parents or caretakers.

Weathers and colleagues held focus groups with parents and caretakers prior to the survey to explain the terms used and to lessen communication barriers during the survey, she says.

"I explained to them what we meant by a 'well check' or a 'health check' and what we meant by good health and poor health, etc.," Weathers notes. "So, it is not as if they had a different standard for judging what was good health and less than good health."

However, it would be incorrect to interpret her

findings to indicate no migrant children are lacking access to needed health services, she says.

Large reporting of unmet need for care

Unusually, both groups — both the users and nonusers of health services — reported a high, unmet need for care in their communities, she adds. More than half of the survey respondents reported that they experienced an unmet need for health care.

“We are still [figuring] out what the results of the survey mean in different areas — but that may be a tip-off that things are not quite as well as they seem,” Weathers notes.

Another difference between users and nonusers, which will be examined in depth in an upcoming paper, is that nonusers were more likely to have never accessed health care services.

“Part of this may be that they are an unexamined population. I used to see children in the clinic all the time from Mexico who never had seen a doctor before at 12 years of age,” she says. “They are saying that they are healthy, but they really haven’t been assessed.”

Other factors that still need more study are an association between age and gender among children getting care.

In this study, younger children were more likely to receive care than older ones, and girls more likely to receive care than boys.

“Some of that may be natural; younger children tend to have more needs than older children,” she says. “But we were surprised about the difference in gender. That may have something to do with the demand for older children — particularly older boys — as workers in the fields.”

The large number of families reporting an unmet need for care, coupled with the association of less-than-optimal health for those children accessing health services, indicates to Weathers that families may seek care only in dire circumstances.

“This seems to be a population whose use of health services is illness-driven,” she says. “All they can make time for is coming in when they are very sick, and that is what the system is supporting. It may be that our system will only allow the emergency access when you really, really need it.”

An area not covered by the recent survey is delayed care, she adds. In her experience, many farmworkers delayed seeking care for health needs that would send many people to a regular physician without hesitation, Weathers says.

“With this study, we did not assess delayed

SOURCE

- **Andrea C. Weathers**, MD, DrPH, Assistant Professor, Department of Maternal and Child Health, UNC School of Public Health, 402A Rosenau Hall, CB# 7445, Chapel Hill, NC 27599-7445.

care, so it doesn’t tell us about the timeliness of care, either,” she notes.

Why the lack of research?

The paucity of funding for research studies in this area may indicate some disturbing biases on behalf of the American public and our health care system, adds Berman.

Governmental attempts to restrict access to Medicaid and the State Children’s Health Insurance Program further marginalize and endanger the lives of people who harvest the food that feeds our country, he emphasizes. Unwillingness to examine the needs of such a large group of children indicates our society has turned a blind eye to the exploitation of migrant workers, he says.

“Why have government agencies and private foundations not supported more studies of these vulnerable, disadvantaged children? Funding research in this area should have been given a high priority,” Berman states. “I suspect the explanation has to do with our fears about being overrun by immigrants and our dependence on their cheap labor, especially in agriculture. Whatever the reason, now is the time for research funders and pediatric researchers to close this glaring and significant gap in the scientific literature. We must all accept responsibility for its existence and work to close it.”

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Software gives migrant workers on-line access

Health information can be stored securely

When Cynthia Solomon's hydrocephalic son required care at a hospital far from his hometown, doctors had a difficult time treating his condition because they had difficulty obtaining information about his medical history and prior treatment.

"He has two shunts and so is shunt-dependent," Solomon says. "I was not with him, and the hospital didn't know what to do. They didn't know where the shunts were, and they couldn't reach his neurosurgeon. It was a mess."

Although health care providers were eventually able to track her down and get some background information, it was difficult for her to convince the hospital staff to discuss her son's condition with her because he was an adult.

Following her son's close call, Solomon, the founder of Sonoma, CA-based Medical Management Resources Inc. (MMR), a software company and consulting firm specializing in medical information applications, decided on a path toward a new product line. Her solution: a program that allows people to securely store medical information on-line.

"People don't realize what can happen if you are traveling out of town or seeking care in an unfamiliar place, and health care providers don't have access to your medical information," she says, "particularly, people with special needs' kids or elderly parents with chronic medical conditions."

FollowMe, the product that Solomon's company developed (www.followme.com), allows users to establish a password-protected profile. That profile contains information about a person's medical conditions, health care history, allergies, and medications. A companion ID card can be printed out that informs health care providers of any chronic medical conditions a person has, what medications they are taking, and how to access the larger profile on-line, in the event of an emergency.

All types of medical information can be securely stored, she adds. Solomon's son has a copy of a CAT scan available on his profile, so that physician's accessing his information can tell where his two shunts are located.

The company is on its third version of the software and is customizing it based on requests

from users and physicians who have seen the application.

"We thought we might get resistance from doctors, but we haven't at all," she says. "They are asking for enhancements, like when they enter information, they want it to be in a 'read-only' field. That makes sense for us, and we can do that."

Visitantes Información Acceso is born

They also are customizing the product for other patient populations. In particular, a grant through Vineyard Worker Services, a nonprofit group that works with migrant agricultural workers in the Sonoma Valley, has allowed MMR to develop a new product targeted to migrant farmworkers, called Visitantes Información Acceso (VIA; www.vwsvia.com).

The software provides the same service that the basic FollowMe software does, except that it is bilingual and has the addition of some other elements to the web site that allow the workers to look up additional information.

The system stores workers' medical information, such as previous physician or hospital visits, prescriptions, immunization records, and diagnoses and treatment plans, eliminating the need for the migrant workers to collect and maintain copies of paper medical records.

"We are a consulting firm, and I work with public health and community-based foundations around special needs populations like the uninsured, elderly, and disabled," explains Solomon. "The migrant farmworkers are a key population here because we are in the Sonoma Valley."

The software is particularly applicable to the needs of this population because the workers move around so much, making it necessary for the individual families to keep track of health care visits in many different sites and settings.

"We've just started enrolling people in VIA, and we've already discovered that they find a number of the features useful in ways that we didn't anticipate," she says. "They really love the physician's digital signatures on immunization records that can be used for school enrollment. And the ID cards [with the medical information] have pictures and can be used as picture IDs."

Because the service comes with a free web-based e-mail account, to allow access to the medical profile, some workers have already been able to better interface with the health care system, she adds.

"We had one person who had filed an insurance claim and was not getting reimbursed," she

SOURCE

- **Cynthia Solomon**, CEO, Access Strategies Inc., 639 Third St. W., Sonoma, CA 95476.

notes. "But when he got the e-mail address, which he can accessed through the Vineyard Worker Services office, he had means of communicating with the company. They started responding to him because he had a definite address and way to be reached, and his claim was eventually paid."

The ID cards have been particularly attractive for immigrant families, and during the process of filling out forms to get family members on-line, the coordinators ask about insurance coverage for children in the family, Solomon adds.

"If they discover a child is not covered, they can tell the parent about Healthy Children [California's program for covering uninsured or underinsured minors] and get them enrolled," she says.

HIPAA-compliant

All of the information collected by FollowMe and VIA is stored securely and encrypted according to specifications mandated by the Health Information Portability and Accountability Act, even though MMR is not a covered entity.

Soon, Solomon believes, most Americans will be storing and tracking their own health information this way.

"I've seen the way the provider-based [online information] systems are going," she notes. "There are about 30-40 out there, and they are not compatible with each other. If I have an internist here, and an OB/GYN in another town — and they're all on different systems. I don't have access to the information on those systems. Our health system is so fragile, and most of us don't know where our medical records are and how they are maintained. We are going to have to take that responsibility." ■

NEWS BRIEFS

High Court keeps Maine RX alive

In a 6-3 decision, the U.S. Supreme Court on May 19 lifted an injunction that prevented the state of Maine from implementing its prescription drug program, Maine Rx, which would require pharmaceutical companies to provide the same discounts to uninsured patients that it provided to persons covered by health plans.

Companies refusing to comply with the discounting plan would not be listed on the state's Medicaid plans list of preferred drugs. (See *Medical Ethics Advisor*, March 2003, p. 32.)

In 2000, the Pharmaceutical Researchers and Manufacturers of America (PhRMA), the industry trade group that represents pharmaceutical companies, filed suit to block the program's implementation arguing that it violates federal Medicaid law and interstate commerce laws.

A federal district court in Maine ruled in their favor, but the First Circuit Court of Appeals in Boston overturned that decision in May 2001. Maine appealed to the U.S. Supreme Court, which agreed to hear the case in June 2002.

The majority opinions indicate that the prevailing justices felt opponents of Maine's plan should have first appealed to the U.S. Department of Health and Human Services Secretary if they felt the measure violated federal Medicaid policy.

In the dissenting opinion, Justices Sandra Day O'Connor, Anthony Kennedy, and William Rehnquist said the district court had correctly blocked the Maine program because the pre-authorization requirement imposed a burden on Medicaid beneficiaries. The case now will return to the federal district court in Maine. ▼

COMING IN FUTURE MONTHS

■ Education for ethics committees

■ Managing non-ethics ethics consults

■ Mandatory testing for bloodborne pathogens

■ Limits on disclosing information to patients

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DNA bank in the works at Howard University

Saying they fear blacks are being left behind as scientists research genetic links to disease, officials at Howard University in Washington, DC, have announced plans to create the country's largest repository of DNA from African-Americans.

Howard, a historically black institution, plans to gather blood samples or cheek swabs from 25,000 people over five years, mainly patients at hospitals associated with the school's College of Medicine.

Floyd J. Malveaux, MD, dean of the medical school, told *The New York Times* on May 27 that genetic information would increasingly find the causes of disease, predict susceptibility to an illness, and choose which drugs would work best for a particular patient. It is important, he added, that the health concerns of blacks are included in this research. In the past, he said, such concerns have often not received enough attention. ■

CME Questions

Physicians participate in this continuing medical education program by reading the issue, using the provided references for further research, and studying the questions at the end of the issue. Participants should select what they believe to be the correct answers, then refer to the list of correct answers to test their knowledge. To clarify confusion surrounding any questions answered incorrectly, please consult the source material. After completing this activity, you must complete the evaluation form provided at the end of each semester and return it in the reply envelope provided to receive a certificate of completion. When your evaluation is received, a certificate will be mailed to you.

1. According to the article, the federal government has challenged Oregon's Death with Dignity Act on what grounds?
 - A. That assisted suicide is murder and cannot be legalized
 - B. That prescribing controlled substances with the intent that a patient may be able to end his or her life is not a legitimate purpose under the Controlled Substances Act
 - C. That states do not have the authority to regulate medical practice
 - D. None of the above
2. Research by the Center for Ethics in Health Care at Oregon Health Sciences University reveals that:
 - A. Physicians' fears of investigation by state medical boards may be a leading factor in the under-treatment of pain
 - B. Physicians' fears of investigation by federal authorities may be a leading factor in the under-treatment of pain
 - C. Oregon is steadily improving the management of pain in patients at the end of life
 - D. Both A and B
3. **Andrea Weathers, MD**, and colleagues at the University of North Carolina studied what population in the article cited in this newsletter?
 - A. Children of Mexican ancestry
 - B. Children of immigrants
 - C. Children of migrant farmworkers in eastern North Carolina
 - D. None of the above
4. The software application that will enable migrant workers to store medical information on-line is called:
 - A. VIA
 - B. MIA
 - C. FollowMe
 - D. MMR

Answers: 1-B; 2-D; 3-C; 4-A