GRANADA, Spain - Inmaculada Echevarria has spent much of her life watching muscular
dystrophy ruin her body. She's been in a hospital bed for 20 years, her movements are now
reduced to wiggling her fingers and toes and she wants to die.

"For me, life stopped having meaning a long time ago. I want them to help me die because I
have spent my whole life suffering," said 51-year-old Echevarria, whose case has triggered
debate in Spain on the rights of people with incurable diseases to seek help in dying.

Euthanasia is illegal in Spain and people who help someone else die can be punished with at
least six months in prison. But

Spain's Socialist government wants to legalize it as part of a wave of liberal reforms that have
largely transformed this traditionally Roman Catholic country.

Under Prime Minister Jose Luis Rodriguez Zapatero, Spain is one of only a half-dozen
countries in the world that have legalized gay marriage. He has also made it easier for
Spaniards to divorce, eased laws on stem cell research, stiffened laws on violence against
women and ended direct government financing of the Catholic church.

If Spain does legalize euthanasia, it would join the Netherlands and Belgium in allowing the
practice, although Switzerland allows some cases of assisted suicide. Opposition
conservatives are against the idea, calling instead for better pain-relieving care for the
terminally ill. They have joined the church in denouncing most of the government's reform
campaign as eating away at Spain's traditional family and religious values.

"Provoking the death of another person, as compassionate as the motives might be, is always
alien to the notion of the dignity of human beings," Braulio Rodriguez Plaza, archbishop of the
northern city of Valladolid, wrote in a letter to Catholics.

The euthanasia initiative has yet to be debated in Parliament, but some are hoping
Echevarria's case may eventually change that. Her plight has drawn intense media interest,
with television and radio talk shows giving the subject a lot of attention.

Newspapers showed pictures of the bed-bound Echevarria on their front pages.

Echevarria, who fell sick at age 11, wants doctors to turn off the respirator that keeps her
alive. It was long ago that she gave up on her dream of becoming a physician herself.
There was a similar case in May of this year: a 53-year-old tetraplegic man in the northern city of Valladolid had a friend secretly disconnect his ventilator. No charges were brought in his death because of insufficient evidence as to who helped him. Echevarria's drama is different because she wants the assistance to be public and administered by doctors.

Fernando Martin, a doctor and spokesman for a pro-euthanasia association called Right to Die with Dignity, insists Echevarria's request is legal. What she wants, he said, is a machine to be unhooked, not an assertive act that would actually cause her death, such as a lethal injection.

"She would just have to be sedated so she would not suffer," Martin said in an interview.

Spanish Health Minister Elena Salgado said last week that Echevarria's case was a delicate matter that was up to the courts.

A patients rights law passed in 2002 says any sick person who is in control of their mental faculties can refuse treatment.

And Echevarria fits the bill, said Rogelio Altisent, chief ethicist at a federation of Spanish medical associations.

"The patient would be exercising her right to renounce treatment, such as assisted breathing," Altisent said.

So far Echevarria's lawyers have had her sign a living will, spelling out that if she becomes mentally incapacitated she wants her life support switched off. But Martin says this is pointless because it will have no effect so long as she remains mentally competent.

What the lawyers need to do is make a request in writing for the respirator to be turned off, and if this is rejected - as expected because the hospital where she is being treated is run by a Catholic order - try to move her to another hospital.

The hospital, called the San Rafael Center, says it has not received any such written request from Echevarria and follows her case through the media. Echevarria's attorney, Ignacio Fernandez, says the paperwork has been held up because of concern that anyone involved in helping her end her life might face charges under Spain's penal code, despite the patient's rights law.

In the meantime Echevarria spends her days reading and watching television. She gave a hospital room press conference in late October but since then has clammed up, refusing visits and calls.

She wants to die painlessly, and cringes at the memory of Ramon Sampredro, a Spanish paraplegic who campaigned for euthanasia, spent 30 years in bed and ultimately died by sipping water laced with cyanide in 1998. He did this after crafting a complex scheme to have friends prepare and deliver the poison in incremental steps so no single one of them could be charged criminally. The story was made into the movie "El Mar Adentro" (The Sea Inside), which won an Oscar for best foreign film in 2005.

"I don't want to die with pain, like Ramon Sampredo. He felt all of what was happening to him and it was a cruel death," she said at the press conference.

She has little family - a son, now in his 20s, whom she gave up in adoption as a baby because she could not care for him after the father died in a car accident. She also has a brother in the northern city of Logrono but has not heard from him in years.

"The loneliness is worse than the physical pain," she said at the press conference. "People treat me well, with kind words, but in the end no one helps me."

Click here to find out more!
2. Mexicans Reject Doctor-Assisted Suicide

Angus Reid Global Monitor: Polls & Research
November 30, 2006

Many adults in Mexico believe euthanasia should not be allowed, according to a poll by Parametría. 46 per cent of respondents disapprove of ending the life of a patient in the event a group of specialists deems that his or her disease is incurable.

In addition, 48 per cent of respondents think it is unacceptable for a doctor to allow a patient, who suffers from an incurable disease, to die with an injection or after administering a drug.

In March 2005, Interior Secretariat human rights coordinator Ricardo Sepúlveda ruled out allowing euthanasia in Mexico, declaring, "Our position is in favour of life. This is a topic that is fundamentally legislative, and any revision would fall in the hands of Congress."

The Netherlands and Belgium allow for some form of euthanasia. In the United States, the state of Oregon legalized assisted suicide in 1994.

Polling Data

Do you approve or disapprove of ending the life of a patient in the event a group of specialists deems that his or her disease is incurable?

Approve
39%

Disapprove
46%

Undecided
15%

Do you find it acceptable or unacceptable for a doctor to allow a patient, who suffers from an incurable disease, to die with an injection or after administering a drug?

Acceptable
41%

Unacceptable
48%

No answer
2%

Not sure
9%

Source: Parametría
Methodology: Interviews with 1,000 Mexican adults, conducted from Sept. 8 to Sept. 11, 2006. Margin of error is 3.1 per cent.

3. Lethal injection method blasted

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Inmate's lawyers call state execution team 'untrained' and 'incompetent'

LOS ANGELES - California's procedures for executing prisoners by lethal injection fall short of standards set by the veterinary profession for animal euthanasia and were formulated with less care than methods in China, the world leader in capital punishment, according to a brief filed Tuesday in San Jose federal court by attorneys for a Death Row inmate.

In addition, the brief asserts that the execution team at San Quentin State Prison is "unlicensed, untrained, unprofessional and incompetent" to carry out its duties.

The brief was lodged as U.S. District Judge Jeremy Fogel prepares to rule on perhaps the most fiercely fought of a number of legal challenges in several states to lethal injection, the dominant U.S. method of execution.

Fogel is expected to rule by the end of the year in the case of Michael Morales, who argues California's lethal injection methods create an unnecessary risk of excessive pain and as a consequence violate the Eighth Amendment prohibiting cruel and unusual punishment.

The California Department of Corrections and Rehabilitation "conducts its executions in an out-dated, cramped gas chamber with an undersized and dark anteroom," from which prison staff are supposed to assure proper administration of a three-drug protocol, the brief says.

The brief also emphasizes that the state uses chemicals "mixed by untrained and unsupervised prison staff, while ensuring that there is no meaningful oversight or review."

Earlier this month, the California Attorney General's Office issued a ringing defense of the state's procedures, maintaining in its brief that "there is no evidence that any prior execution resulted in the unnecessary and wanton infliction of pain."

But the 274-page brief filed by Morales' attorneys finds fault with virtually every aspect of California's administration of capital punishment, frequently citing admissions made by state personnel during the proceedings.

For example, the execution team leader, identified only as "Witness No.5," said that for the past eight executions, he did not require team members to practice mixing the first of three drugs, sodium thiopental, which is supposed to anesthetize the inmate before the second two drugs - pancuronium bromide, which paralyzes the inmate, and potassium chloride, which causes cardiac arrest - are administered.

One of the key arguments in the Morales case and in several other lethal injection challenges is that the anesthetic has not been properly administered, with the result that the condemned inmate experiences excruciating pain but cannot express it because he is paralyzed.

Witness No.4, a licensed vocational nurse, said in a deposition that she never received any training for mixing thiopental.

The first time she prepared it was the night of an execution, she said.

The California Department of Corrections "has failed to comprehend both the importance of properly preparing (the drug) and the difficulty of doing so," according to the brief filed by Los Angeles defense lawyers David Senior, Kathleen Saenz and Benjamin Weston.

In response to a question from the judge, the defense brief indicated that it might be less risky to conduct executions using a single drug.
Still, Morales' lawyers cautioned that there also would be risks with a single-drug protocol. Significant problems with the execution chamber and drug delivery apparatus, including cramped quarters, poor lighting and bad sight lines, still exist.

Fogel asked the lawyers how the execution procedure could be improved. But Morales' lawyers cautioned that they were ethically constrained in the answers they could provide, saying they could not "be put in the position of designing for the state its execution procedure."

Defense lawyers said there may be a better execution anesthetic than thiopental. But, as long as the protocol includes pancuronium bromide and potassium chloride, "it is imperative" that the state provide for a clinical, bedside evaluation of anesthetic levels by a trained professional, the brief said.

The defense said it "should not be that difficult" for the state to retain such a doctor, although a brief filed by the California Attorney General's Office earlier this month asserted that such a requirement would effectively shut down capital punishment in California because leading physicians' organizations have urged their members not to participate in executions.

Morales' lawyers criticized state officials for failing to adequately research either their original lethal injection protocol or a modified procedure adopted in the face of his legal challenge. In contrast, they said that Chinese government officials conducted detailed experiments on animals before executing humans by lethal injection.

Morales' lawyers argued that the state needed to bring its execution procedures out into the open.

"For the past fourteen years," the Corrections Department has undertaken the recruiting, screening and training of execution team members "in total secrecy. That secrecy has permitted the execution system at San Quentin to operate in an unbelievably dysfunctional manner," the brief said.

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4. Dying with dignity in NZ

Saturday December 2, 2006
By Catherine Masters

Making their own decisions can be a great consolation to patients. Picture / Getty Images

Doctors have been gathering at Middlemore Hospital in South Auckland this week to talk about death.

It is a subject they would like us all to talk about but at the same time they are nervous about what might appear in the newspaper. They fear a backlash. Deciding when to let people live and when to let them die is a sensitive business.

But doctors have to deal with it and they say we should all think about it.

Take the case of a frail elderly woman who lived in a resthome.

She had severe dementia. She had to be secured to be taken by ambulance for her visits to hospital, where she needed dialysis for three to four hours at a time.

She didn't know where she was. It was a miserable life.
This is a real case. If she'd had any way of knowing what was to come, the woman might have said she would not want to have any treatment.

It is not just the elderly who need to talk about death, the doctors say. There are those who may be younger yet will develop chronic illnesses, or those who are destined to be hit by a bus and become brain-dead, or have brain damage of such severity that life would become an ordeal. They might want to die but have relatives who desperately want them alive.

The doctors and specialists in South Auckland are not ghouls who want to end the lives of the very ill. They are respiratory specialists, renal specialists, intensive-care specialists, grief specialists, palliative-care specialists. They are the people you want around should the worst happen.

Money is an issue, but not the main issue, they say. About 70 per cent of the health budget is spent on the last two years of life. It's a lot of money and it means that sometimes other people, perhaps a young mother with two little girls (another real case) who may need drugs or treatment, will not get them.

Mainly, though, it is about quality of life. Addressing the doctors at Middlemore is Australian intensive-care specialist William Silvester, invited by Middlemore's clinical head of medicine, Jeff Garrett, to talk about the system Silvester has instigated in Victoria.

His programme, Respecting Patient Choices, is already running in eight hospitals in the state. Funded by the Federal Government, it will be piloted in every state and territory in the country.

As an intensive-care specialist, Silvester had become concerned about the number of patients being treated in such a way that if they had been able to tell doctors their wishes, they may have rejected treatment.

His programme is about what doctors call advance-care planning, where people choose different options about what they might want in the future.

The programme is running in hospitals and in resthomes - and in the resthomes there has been a big reduction in the number of patients being inappropriately transferred to hospital to die, Silvester says.

"They're being kept comfortable in the nursing home. They have their family and friends at the bedside and they're allowed to die with dignity and peacefully instead of being transferred to hospital, where they might end up dying on the emergency department trolley while they are waiting for a bed on the ward, or up in the ward being cared for by people who don't know them."

Silvester says the resthome residents think it is fantastic that someone has bothered to talk to them about these matters, because often the elderly in such places feel disempowered and ignored.

"They indicate whether they want to be going to hospital if they deteriorate. They indicate whether they want palliative care or to be aggressively managed. They indicate a lot of personal things.

"They say, 'When I'm dying please leave the curtains open because I don't like the claustrophobia of the curtains being around the bed'. Or they might write, 'Please when I'm dying I'd like to have a vase with irises because it's my favourite flower'.

"Or they might write they want country-and-western music playing, and they'll often say they want a particular priest or minister to come, or they might want rosary beads in their hand, or they might want a penny in each hand for the ferryman."
"So for each of them, it's very personal and intimate response - and that's fantastic."

Families find the discussion helpful. Bringing up death is not easy. Sometimes they fear staff will interpret it as their wanting to pull the plug on mum or dad when really they just want to care for them in the best way.

Silvester says that as yet he has not looked at whether money is being saved, partly because the programme can be portrayed as a government-sponsored way to save money.

This is not what it is about, he says. "We're finding, paradoxically, it's protecting the vulnerable because they're being given an opportunity to say what they do and don't want under circumstances where they are normally not even asked at all."

Respiratory specialist Jeff Garrett would like to have a pilot programme at Middlemore but says he is not yet sure exactly what is required.

But on ward rounds he often sees people who are inappropriately treated and who, given all the information on what they can expect, would prefer to die with dignity.

Patients in New Zealand with a wide range of chronic medical conditions are not managed as well as they could be or should be, he says.

Garrett talks about one of the best deaths he has witnessed. A mother in her late 30s who had respiratory failure came forward for lung transplantation. She was so ill she was just "surviving" and when this happens people focus in on themselves.

"That's the only way they can survive," Garrett says. "They have no effort, physical or any other way available to commit to anybody else in the family."

The transplantation was a success and for two years her young daughters saw a new mum and the family had a fabulous life.

But then came chronic rejection.

The mother said she was heading back where she was before, saying: "It's awful, I'm going back into myself again and I'm becoming reasonably dependent on the family." It was agreed that her next infection would not be treated.

"She rang me and she said: 'I've got an infection and I'd like to come and die in hospital'. And she did and she had a lovely death and the whole family came and said goodbye."

Although this sometimes happens, Garrett says there should be a better system ensuring all patients' desires are taken into account.

There would need to be careful training for all involved and legalities and safeguards would have to be thoroughly developed.

"What it's doing is giving the control back to the patient and having the depth of discussion that allows them to make those informed decisions about their care."

Stephen Streat, an intensive-care specialist from Auckland Hospital and head of the organ donation programme, attracted controversy last year by suggesting that death and dying be part of the high-school curriculum.

He fears an Americanised healthcare system, where doctors simply fall into line with what the family wants in order to avoid complaints.

In America, the question is around who has the right to decide. Here, the discussion is about what the right thing is for the patient.
In intensive care at Auckland Hospital, the first meeting with the family outlines the seriousness of the condition. If the patient might die, the family are told that.

"At some point it may become very clear to all of the treating team that continuing to treat the patient would either only prolong their dying, or, worse, have the possibility of allowing them to survive without recovery in a condition where they and the family would prefer death."

Over time, a mutual decision might be made to withdraw treatment. It is not a painless process and is emotionally draining, Streat says.

He believes there is a widespread lack of awareness about the limits of medical technology, a naive belief that technology is all-powerful and that any health problem will respond to unlimited money, that everything is treatable. This is not the case.

Streat thinks that one of the reasons people were upset at his suggestion that death and dying be part of the curriculum is because people are no longer accustomed to death.

In the 1930s, 10 per cent of the population did not make it past 5, and death as an adolescent was common.

In late Victorian times the average age at death was 40. Now it is 80.

Streat is supportive of Silvester's initiative which has taken the discussion about death out of the hospital and into the community. It's a start.

The passive approach prevails

Johan Rosman has an unusual perspective on end-of-life planning. The head of renal medicine at Middlemore Hospital is from the Netherlands, where euthanasia is legal. He has also worked in Germany, where every effort is made to keep patients alive, no matter how old and sick.

Rosman is shocked by people who think doctors in the Netherlands kill patients who are not contributing to society. He says it is rare for doctors to take part in active euthanasia, where perhaps someone with cancer has decided they do not want to go on in pain, and there are strict criteria to follow.

Passive euthanasia is more common and is humane, he says. And it already happens in New Zealand, when patients make choices about treatment.

With conditions such as end-stage renal failure most countries say, "you have to do dialysis otherwise you will die", and that's where the thinking stops, Rosman says. "We should ask ourselves, 'do I do this patient any favours by proposing dialysis?'"

Dialysis is an aggressive treatment which cleans the blood of waste. What your kidneys achieve 24 hours a day, seven days a week, is reduced to aggressive sessions three times a week.

Usually people feel miserable, nauseous and exhausted before they come to dialysis, and miserable afterwards. "It's a tough life, so you have to ask yourself from an end-of-life perspective continuously during that treatment, is this worth it?"

He sees older people with severe diabetes and two amputated legs who might feel it is not worth it. If they say stop, the staff are happy with that. The patient will die peacefully within a few weeks.
But sometimes families push them to go on for religious or cultural reasons. "It's sad, it's really sad," Rosman says.

Rosman hopes the seminar will help health professionals to lose their fear of talking about death.

"As healthcare professionals we are trained to make people healthy, to keep people alive, but I think a very important task of healthcare professionals is to give the people who are not going to survive a human and, especially, dignified way of getting out of this life."

"Dying is as much part of life as being born. We should not try to hide from death."

END

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