A Vulnerable Place

A remote Alaskan village. An elderly woman with Alzheimer's disease. The son who cares for her. These are the key elements in an experience that a DMS student had during one of her clerkships. The encounter took place over a decade ago, in a singular setting, but its essentials are timeless and universal.

By Emily R. Transue, M.D.

The sky is clear and the sun is shining brightly over the small Eskimo village of Kururak. Such a day is rare, the villagers say; there are only about a dozen a year. We have brought the good weather, they tell us—the doctor, the local health aide, and me, a medical student. Indeed, it has been fair and warm ever since we flew into town this morning.

But now a cold breeze begins to blow in across the river, and a chilling mist rises from the sun-warmed grasses. I tighten my scarf around my neck as we walk quickly in single file along the narrow wooden boardwalk that runs through the village. We pass the church, the store, the large and modern-looking high school. I look up at the low, rolling tundra plain, at the hills that rise slowly but majestically to the north and south of the village. The pipe that brings drinking water down from the hills glitters softly in the sunlight. The river plain stretches to the east. The ocean lies behind us.

Transue, a 1996 graduate of Dartmouth Medical School, is now an internist in Seattle, Wash. The incident she relates here took place when she was a third-year DMS student, during her family medicine clerkship in Bethel, Alaska. It is a true story, though identifying details have been changed to protect patient confidentiality. Transue began writing patient narratives while she was a student as a way to process the emotions of practicing medicine. Many have appeared in Dartmouth Medicine, *and a collection of her pieces was published by St. Martin's Press in 2004 as a book—*On Call: A Doctor's Days and Nights in Residency. *She has been invited to speak about her writing at the annual meeting of the Association of American Medical Colleges in October.*

The Alaskan village in this photo illustration and the people pictured on the succeeding pages are not those in the story related here—but are typical of the 49th state.

It is late August; summer is barely waning, but already this seems a chill and vulnerable place. I cannot begin to imagine what it must be like in February—when the tundra is covered in snow and ice and the bitter wind is blowing unhindered across the frozen waters of the Bering Sea. I shiver at the thought and draw my parka closer. Who would think, I can't help but wonder, to build a village in such a place, along a narrow, entirely unprotected spit of land between the flooding river and the Bering Sea?

We walk in silence. We are on our way to pay a home visit to the only bedridden patient in the village. She is an old woman and has not left her bed in years; she has Alzheimer's. Two sons care for her. Her husband was recently hospitalized in Anchorage with a bad infection in his leg. The doctors think he may walk again, but they doubt he'll ever be well enough to return to the village.

We approach the house—a small wooden structure perched on stilts, like all the buildings here, to protect them both from floods and from the constant freezing and thawing of the tundra. I continue to be amazed at how haphazard and insubstantial all the houses look from the outside. But appearances are deceiving. The patched plywood walls are lined with several feet of insulation and are sealed tight against the bitter winds.

We walk up the steps and knock on a weather-beaten door. "She has a vicious little dog," whispers the health aide, who does not like dogs. The door opens, and a blast of heat engulfs us. My glasses steam up as I step across the threshold. The fog slowly clears and I see the others kneeling to take off their boots, and the old woman's son standing in front of me.

"Shut the door," he says. I realize I have been unconsciously holding it slightly ajar, clinging to the last wisps of clean, cool sea air.

PHOTO ILLUSTRATIONS BY JENNIFER DURGIN

I wonder what will happen when the old woman and her husband die. What happens to a house filled waist-high with stuff that no one needs, in a village of 300 people, hundreds of miles from anywhere? The question of disposal is a serious one in the far reaches of Alaska.

The house is oppressively hot and smells faintly of urine. Quickly and guiltily, I pull the door closed behind me.

The "vicious" dog is at my feet, clipped to a chain in the low entryway. She barks once or twice, then wags her tail hopefully; I kneel to pet her. She looks like a puppy at first glance, but as she clambers into my lap I realize that her feet are small. She's an old dog, though with puppyish proportions. Beside her on the floor is an old, rusty birdcage, empty, its door hanging open.

Without preamble, the son leads us into his mother's room. The bed, which fills most of the room, is huge—queen-size, I guess at a glance. It's piled high with blankets, towels, pillows, boxes of Pampers, and folded piles of extra sheets. It takes me a second to even see the patient amidst all the piles—a small, curled form nestled in the middle of them. She lies on her side, quiet and still. Her head is resting on a pillow, her eyes are closed.

She has a classic old Eskimo face, carved with wrinkles, thick with character. The Native Alaskans in this part of the state are Yupiks; although some other tribes now consider the term "Eskimo" to be offensive, I've learned that it's how the Yupiks still identify themselves. I have been taking pictures of villagers as I travel around, elders and children mostly. I long to take one now but know that I can't ask.

On the bed at the old woman's shoulder is a small pile of dark, almost round objects that at first glance appears to be a heap of rabbit droppings. I look more closely and realize that it is a rosary made of small, dark wooden beads.

"She's awake," says her son. "She just doesn't open her eyes—she hardly ever does anymore." I wonder whether it is the honed instincts of a long-term caretaker, someone who knows her every expression, every posture, that tell him she is awake when I am able to detect no outward sign; or whether it is wishful thinking, some deep need to believe that she is still capable of waking.

Does she ever move? I wonder. *Does she speak?* As if in answer to my thoughts, he goes on: "She gets muscle aches sometimes. She moans." He pauses, then adds: "It's been years since she's spoken. Sometimes she tries to say a name. Every once in a while—very seldom, now—an old family friend will come to visit, and if they talk, I think she pays attention for a little while."

As I turn back to look at her lying in the bed—and note the strange, abbreviated shape under the blankets—I suddenly wonder if she hasn't got any legs. I search my memory for critical details I may have forgotten when I was reading her history: Is she a diabetic? Has she had amputations? But as her son tenderly draws back the covers, I realize that she does have legs after all—slight, emaciated legs curled tightly up against her rounded belly, strictured and useless.

We survey her for a long moment. Her skin is golden brown and smooth, stretched across her gaunt frame. The curved sweep of her pelvic bones is prominent, her legs and arms delicate, her stomach gently protruding. If she were an alien creature, a new kind of being I had never seen before, I would have said that she's beautiful. She has the thin, tender, helpless appearance of an embryo or of a newborn calf not yet able to stand.

She is perfectly clean, here in this place where there is no running water, much less bathtubs or shower stalls. Her skin is unblemished by the sores or pressure ulcers that usually curse the bedridden. She has clearly been exquisitely well cared for.

First we listen to her lungs and her heart; then we prod her belly and her extremities. We hope not to find anything, so we won't have to face the questions that would be raised: Would we treat a pneumonia if she were to develop one? How aggressively do you manage someone in a condition like this? But we don't find anything.

"Technically," the doctor had said to me quietly as we were loading our backpack to come over here, "we should do a Pap smear, a pelvic, and a rectal and draw a bunch of blood. But think about it—we wouldn't treat a cancer if she had one. She's not strong enough to handle surgery, or even radiation or chemo. You have to draw the line somewhere, and I refuse to torture her."

We need to roll her over to examine the rest of her skin. Her son lifts her tenderly, murmuring a soft apology in her ear and setting her down expertly on her other side. She is lying on a pile of diapers, some adult, some child-size; he rearranges them carefully, making sure there are no gaps. The faint smell of urine that I noticed in the entryway is stronger here; he sniffs at one of the diapers, throws it away, and carefully replaces it. Along her hips and buttocks, she bears well-healed scars from several large pressure ulcers. Her skin is perfect now, but she clearly had problems in the past.

He draws a blanket over her after a moment. "It's cold," he says, apologetically but firmly. I shiver paradoxically, feeling uncomfortable in the excessive heat.

The room, I note, glancing around, is as cluttered as the bed. A hanging rack that's braced against one wall is jammed with clothes on hang-

ers—most of them at least 20 years old, I judge from the colors and fabrics. The floor is piled high with more blankets, rolls of paper towels, baskets filled with shoes, bags of clothing. On the wall above the bed hang two crosses, a Madonna, and a depiction of Christ, all of them rendered in faded pastels and soft focus.

When the exam is complete, and it is clear that our patient is not going to open her eyes or respond to us, we retreat to the living room to talk with her son.

I now notice something that I barely had time to absorb on our way in. The house is small, tiny by outside standards but average for Kururak. There is the bedroom, a kitchen just large enough to hold a small table, and a living room with a single small sofa. But the extraordinary thing about the house is that it's packed to a depth of nearly three feet with stuff.

The place isn't dirty—dusty, yes; dust couldn't help but collect in such a setting. But there's no garbage anywhere, and each object was clearly, at some point, deliberately placed in the spot where it sits. Rather than dirty, or messy even, the house is the theoretical extreme of cluttered. Every surface—the sofa, the kitchen chair, the table—is buried in stacks of magazines, clothes, possessions of every description. Not an inch of horizontal space is visible.

There is a narrow, curved passageway in the middle of all this stuff—a channel just wide enough for a person to pass through. It reminds me of the rivers we flew over on our way to Kururak this morning, weaving canals cut by water seeking a route across the tundra. The whole house feels evolved, carved out by time rather than by a conscious hand.

The doctor and the health aide sit on the sofa, after clearing off enough space for themselves. I perch on the edge of a chair piled high with old *People* magazines. The son stands, facing the three of us, shoulders erect, like a man before a firing squad. I offer him my seat; he shakes his head. Uncertain, I shift to sit on the floor instead. He remains standing.

The doctor reassures him about the exam, saying that nothing looks new or alarming. Then she goes on to discuss treatment options for urinary tract infections—UTIs. The old woman gets terrible UTIs, which are a common problem in the elderly. Her son catheterizes her every day. He has a single plastic catheter that he cleans and reuses; disposable replacements have been ordered again and again, but they never come. Often her urine is thick and white with pus.

She's been tried on many different medications for her recurrent UTIs. The doctor suggests trying a new one and weighs with the son the advantages and drawbacks of giving her a pill every day to prevent the infections versus treating them as they arise.

As the conversation flows around me, I mentally catalogue the items in the room. I count six thermos bottles, arranged in a neat clump. Two TVs, neither of which appears to work; a VCR; half a dozen remote controls. Four telephones and some empty telephone boxes. Mountains of books, their titles unreadable from where I sit, and at least a hundred old comic books crammed onto a shelf. It occurs to me fleetingly that these would probably be worth quite a lot of money in the Lower 48 but that they'll probably end up in a fire or floating along a beach.

There are a dozen fishing poles and eight or nine rifles. Children's board games, playing cards, and jigsaw puzzles. One large completed puzzle, showing a fishing scene, has been mounted and hangs on the wall. There are several clocks, their hands unmoving; stacks of china dishes; a large box of clothespins.

Toward the front door, the stuff takes on a garage theme: several cans of WD-40; a toolbox; rusty tin cans filled with screwdrivers, wrenches, hammers, other tools. A motor is propped in the corner, and chunks of a disassembled engine lie about. There are fishnets, tools for mending them, piles of weights and buoys. There is the little dog, curled sleeping on the floor now, her bowl and a large bag of dog food nearby. And the old birdcage.

There are hats, dozens of them, scattered everywhere: fur hats with earflaps, baseball caps, knit caps, a cowboy's Stetson. Gloves in similar variety and abundance. Mountains of boots and shoes.

There are several cast iron pans, and a number of tin pots. The central passageway is lined mostly with cans of food: tomato sauce, tuna fish, and jars and jars of baby food.

On the old wood stove in front of me is a small jungle of five or six plants, tall, pale, scraggly, and unkempt. They look on first glance to be near to dying, but on further assessment to be strangely healthy—the backhanded health of the untended and uncared for, the unlovely hardiness of those who have learned to survive in less than ideal conditions.

The walls are as tightly packed as the room itself, no inch left uncovered. Company pictures of the National Guard predominate, dozens and dozens of them, though I am unable to pick out the individual family members from the rows of stiff, dark-uniformed men. Baby pictures, pictures of children. A few wedding photos of assorted vintage. A lot of religious paintings along the same vein as those in the mother's bedroom.

One large floor-to-ceiling bookshelf is crammed with bric-a-brac. China cups, vases, figurines. Feathers, boxes, jewelry. Bits of wood and bone smoothed and bleached by the ocean. String figures, children's crafts and art projects. Native crafts are prominently missing, but I know that the fur dolls and intricate woven baskets sold in town are expensive and probably aimed more toward tourists than the villagers themselves.

Who was she, I wonder, *the owner of this house, who lies so still in the next room? What was she like?* I look for an answer in this vast accumulation of her possessions, but (other than the fact that she never threw anything away) I am unable to find one. There is too much noise, too much clutter.

I wonder what will happen (sooner, or later, as the case may be) when she and her husband die. What happens to a house filled waist-high with stuff that no one needs, in a village of 300 people, hundreds of miles from anywhere? The question of disposal is a serious one, I have come to realize during my time in the far reaches of Alaska—in places too small to maintain effective dumps, where there is nowhere else for waste to go. Transport is expensive. People are willing to pay the shipping cost to bring things in, but in a cash-poor economy paying to have something taken away is an unlikely use of scarce resources. And stuff of a disposable but enduring kind—aluminum cans, plastic trinkets—is relatively new to this culture. Garbage as we know it was not something that formerly had to be dealt with in an economy based on fish and seals and caribou. The result is a lot of trash strewn around the villages, on the beaches, even across the tundra.

"I talked with your father's doctors in Anchorage this morning," continues the doctor. "They aren't sure he'll ever walk again. They feel quite certain that he won't be able to come back here or to help with her care. We thought perhaps they could be placed in the same facility."

What will become of it all?

"It must be incredibly difficult for you," the doctor is saying to the woman's son, pulling me out of my reverie.

"Well . . . " He looks uncomfortable, discussing such a question with strangers.

"What do you do?" she asks. "Do you fish?" This is almost the only occupation for men in the village.

"Subsistence fishing, yes. I got out a few times this summer—we ought to have enough to get through the winter."

"And commercial fishing?" the doctor continues. She knows that food in the drying house is critical, but cash is important, too.

"I used to. But since . . . " He glances toward the bedroom. "No. Not anymore."

"So much for you to give up," murmurs the doctor.

He looks uncomfortable again and clears his throat a few times, as if trying to express something inexpressible, something we couldn't possibly understand. "It's . . . " He begins speaking, then stops, then tries again. "We were difficult kids," he says finally, fidgeting slightly, looking away. "She . . . she never scolded."

Suddenly he offers the doctor his hand, palm down. She looks confused. "I have this problem with my fingernails," he says.

She examines them. "They look all right," she says.

"Sometimes they swell up," he says, "And get all red."

"Around the nail?"

He nods.

She asks a few more questions and studies his hands again. "I think it will be okay," she pronounces finally. But she still looks confused. It seems out of keeping, somehow, for him to bring up such a minor complaint, or indeed to offer anything about himself.

A few minutes later we are talking again about his mother.

"She has trouble," he says, "with her anuk"—using the Yupik word for bowel movements.

"What kind of trouble?"

He opens his mouth, then closes it again.

"Does she need enemas?" the doctor asks.

"No . . . " His voice trails off.

She waits.

"I have to take it out," he says finally. "She can't push."

The doctor's eyes widen. And flash with sudden understanding. "No wonder," she says to me later, "he was so concerned about his fingernails."

"I . . . I don't mind," he adds quickly.

The doctor raises her eyebrows.

"She would have done it for us," he says.

"Have you ever thought about a nursing home?" asks the doctor gently, at last. That was one of the main purposes of our visit, to broach this subject.

"She said once that she never wanted to be carried out of this house on a stretcher," he says. There is a sing-song quality to the sentence, as if it had been repeated many times before.

"Do you know why she felt that way?" the doctor asks quietly after a moment.

"She didn't want the neighbors to see her carried out. I think she would have been ashamed."

For a second, I wonder if something as simple as a quiet, late-night transport would solve the problem. Then, in the next instant, if it is more shameful to be carried out alive than dead. She has to leave somehow, sometime.

"Do you think there's anyone left inside to be ashamed now?" the doctor asks, very gently. "I'm not trying to answer that, I'm just wondering what your thoughts are . . . "

He doesn't respond.

Finally he says, "My father always said that if we put her in a nursing home she wouldn't last long." His eyes look troubled.

Would that necessarily be such a bad thing? I see the question in the doctor's eyes, but she leaves it unspoken.

He sighs, his face dark and clouded. There is a strange unguardedness about him. He must be nearly 50, but somehow he seems too young, too innocent, to be carrying the burden of this question.

"I talked with your father's doctors in Anchorage this morning," continues the doctor. "They aren't sure he'll ever walk again. They feel quite certain that he won't be able to come back here or to help with her care. We thought perhaps they could be placed in the same facility, in Anchorage; that way they could be together. She wouldn't have to be alone."

The son pauses for a long time, lost in thought. "It's been like this so long," he says at last. "Five years. I guess I just don't know any other way anymore." He speaks slowly, and there is a curious absence of undercurrent to his words. He does not seem to be saying either that five years is long enough or that having gone this far he feels he must keep going. I think he means just what he said—that he can no longer envision any other way of living.

"He won't walk again?" he asks suddenly, changing the subject back to his father. He glances up, then down again at the floor. His voice and face

barely register grief; he rubs his shoulder and arches his back, as if adjusting to the addition of yet another weight to everything he has learned to carry.

"Maybe," the doctor says. "But come back, probably no."

Her final word hangs in the air for a moment before she continues, asking, "It's you and your brother who take care of her, right? Are there any other siblings?" These are relevant questions, as well as a break for him from the harder ones.

"I have two sisters who moved away." He speaks quickly now, seeming relieved, glad to talk about anything other than his mother. "And a brother in the village. My oldest brother died when I was eight. It was a big change; suddenly I was supposed to be the older brother. I'd always looked up to him, worshipped him—he was my hero. There was a shooting accident. He was hunting, he got shot."

His tone is matter-of-fact, but his eyes look lost and helpless. There's the same inability to defend his heart against tragedy, the same taking on of impossible responsibilities; wounds that he felt at eight seem to be replaying themselves decades later.

We discuss the things that are entailed in caring not just for his mother but also for the house—carrying water from the village's central source, removing waste, stoking the fire, tending to her dog and her bird . . .

"There's a bird?" It isn't important, but I'm startled by this new piece of information.

He nods. "She flies around the house. I don't think she's in there now." He bends down and peers into the birdcage, which is indeed unoccupied. "She's probably in the kitchen—hiding most likely. She's very shy. She got outside once, by accident; she was terrified. Doesn't know how to catch bugs or look for seeds. And the wild birds, they scared her something awful. I didn't know what to do. Finally I took the cage outside and she flew right into it. She wouldn't come out for days."

He pauses. Seeming to not quite know what to do next, he goes looking for the bird. "Here she is," he calls from the kitchen.

I walk in and crouch beside him on the floor. "She's under the table," he says. And there she is, sitting on one of the chairs, a small brown sparrow. She cocks her head at me anxiously. "She's awfully shy," he repeats. I don't think I've ever heard that word applied to a bird before, but it seems to fit.

She flies up and settles for a moment on the windowsill, still eyeing me. She has landed expertly amid a cluster of china puppies arranged compactly on the sill. She chirps and flutters her wings. Then in a whir of soft brown feathers she is gone.

I remember being told when I was little—or maybe reading somewhere—that when Eskimos got old and were unable to work, they'd walk out onto the ice and die. *Was that true,* I wonder, *or just a myth?* If it did happen, how different from the scene before me now. Once the responsibility—the duty, the honor—would have been hers. Now it is her son's. She can no longer go out onto the ice herself. Should he be expected to push her? I ponder these matters as the doctor, the health aide, and I walk back in silent single file along the boardwalk, leaving behind us questions raised but unresolved.

Dusk has fallen—the long and eerie subarctic twilight. I hear waves breaking on the shore. A gull cries mournfully into the wind. ■

An eye-opening eight weeks

As the adjacent narrative suggests, practicing family medicine in rural Alaska can be an eye-opening experience for medical students from the Lower 48. Although Native Alaskan villages are rich in cultural traditions, they usually are poor in resources and infrastructure. In many ways, they're more akin to a rural village in a third-world country than to the rest of the United States—even a small town in a remote area.

Places like Kururak often lack indoor plumbing, have weak economies, and are burdened by high rates of alcoholism, diabetes, and other illnesses—which is why Dartmouth has been sending medical students to Alaska since the late 1970s. Student interest in the 49th state grew quickly, and by 1991 a formal relationship had been established with a hospital in Bethel, Alaska. The hub of the 75,000-square-mile Yukon-Kuskokwim Delta region, Bethel has a population of about 6,000.

Now, each year, up to six third- and fourth-year medical students experience the family medicine clerkship based there. Working in Bethel and the region's 50-plus villages exposes students to a "public health perspective, prevention, community involvement, home visits—all of those things," explains Dr. Catherine Pipas, director of DMS's family medicine clerkship. It also gives students a chance to see a "more broad spectrum of what they can do with their skills in family medicine and primary care," she adds.

"My decision to choose primary care as a career was definitely solidified in Bethel," says Dr. Emily Transue, DMS '96 and the author of the adjacent feature. "Sitting in a clinic in a big hospital, it was harder to feel that you could really impact someone's life, whereas doing a home visit in a village, [the patient's] needs and your potential to help are really clear.

"Being dropped into a village of a few hundred people," she continues, "you get a much clearer sense of the interactions between the community as a whole and the individual patient than you ever have in a larger place."

In addition to the Bethel clerkship, Dartmouth medical students can do their eight-week family medicine rotation on a Navajo reservation in Tuba City, Ariz.; in the Florida Keys; in Providence, R.I.; in two locations in rural Maine; and in multiple locations in Vermont and New Hampshire. Where third-year students end up for this required clerkship is based on a lottery system. In addition, fourth-year students interested in family medicine can do an elective rotation at many of these sites—including Alaska, Arizona, and Florida.

"The most important thing I took away" from Bethel, says Joan Hier, DC '01 and DMS '07, was "how to provide continuity of care with thoroughness and adaptation, given limited resources." Hier is not pursuing family medicine but is considering two other primary-care disciplines—internal medicine and obstetrics-gynecology. And, she adds, she'd like to work again in "a place like Bethel, even if only a few weeks a year."

Jennifer Durgin