

Translating the language of loss

Hospice 9-13-03
Hospice Caring Project expanding access for Spanish speakers

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The word *hospice* doesn't have a direct translation in Spanish, but the Zárate family understands what it means.

Jose Zárate Martinez was a joyful man. Father of five, husband of Gema Zárate Sanchez, and florist, he loved his music loud and his family near.

In 1998, Santa Cruz doctors removed a large malignant tumor from Jose's pancreas

and told Gema and the three children who live in Santa Cruz — Veronica, Valentin and Felipe — that there was a 50 percent chance it would return.

A year later, when Zárate returned to the operating room to correct an intestinal problem caused by the first surgery, the cancer had roared back.

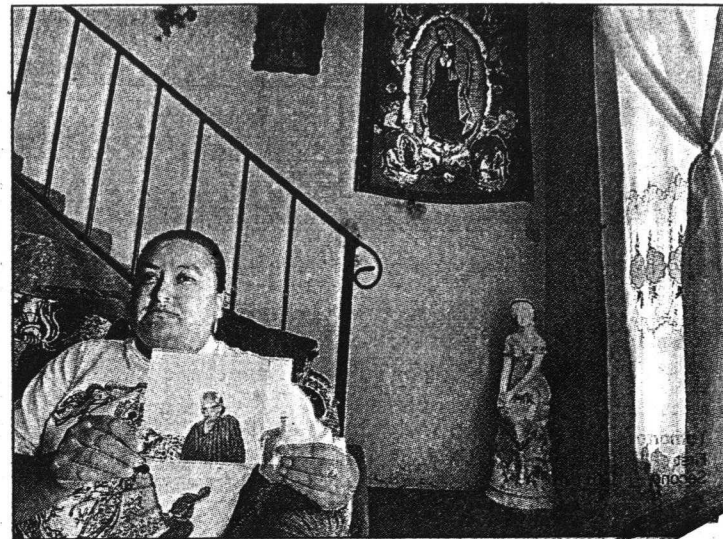
When chemotherapy couldn't stop the cancer's growth, Jose Zárate's doctor recommended the family to Hospice Caring Project of Santa Cruz.

"It was very difficult for us to accept *hospicio* at first," said Veronica Zárate, using the Spanish word that means 'orphanage.' She's a small, compact woman sitting on a worn couch, her young daughters hovering

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Shmuel Thaler/Sentinel

Veronica Zárate Sanchez proudly holds a photo of her father Jose Zárate Martinez, taken just days before his death in January 2001.



Hospice

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behind.

"They talked to us about what we could expect, and those were the things we didn't want to accept."

When the nurses came to the Zárate's Beach Flats home to make Jose more comfortable in his last months of life, the family — three generations in one home — realized they had some misconceptions about Hospice.

Not only did the nurses and social workers speak Spanish, they seemed to understand what the family was experiencing.

"Some Mexicans might think that Hospice is only for gringos or those who belong to a certain religion or those who have documentation," said Veronica.

"But we found out it's for everyone. They respected us regardless of where we came from or how much money we have or what our religion is."

Not only did Hospice provide nursing care and pain relief for Jose, but Christmas presents as well for Veronica's small children Paula, Vanessa and Juan.

When the doctor predicted that Jose's days were few, Hospice helped the two Zárate children living in Mexico — Aurora and Martin — get the emergency visa they needed to cross the border and join the family.

"Hospice has been indispensable," Veronica said. "Especially in those last days. They gave us so much more support than I expected."

Spreading the word

While the monolingual Spanish-speaking population of Santa Cruz County is growing, the word hospice is rarely found in their vocabulary. Spreading the word and translating the many services — medical, physical, emotional and spiritual support for patient, family and friends — provided by

Hospice Caring Project of Santa Cruz is the job of Bruce Hobson.

Two years ago, Hobson — a lean, intense man with a tangle of gray and black hair — was hired as clinical outreach worker for Hospice's Center for Grief and Loss. A native Santa Cruzan — and graduate of Pacific High School — Hobson has lived and worked as a health educator in rural Mexico most of his adult life, most recently with the Mexican Health Department's nutrition program in Chiapas.

Besides providing grief counseling for local Spanish-speaking families who have lost a loved one, he works to improve accessibility, raise awareness (and money), and promote equality in all Hospice services.

"For most of the Spanish-speaking community, Hospice doesn't exist," he said.

"And that's true anywhere you find a large immigrant Latino community. Our work now is to find out from Spanish speakers what they need and what they'd want it to look like."

According to Hobson, the key to increasing equality of service is awareness.

"Most of our potential clients don't even know that the services are available," he said. "They think: 'I'm Mexican, I don't speak English. I have no money, no health insurance, no documentation.' But we want people to know that the doors are open."

Awareness is growing slowly,

with a recent yearlong series on end-of-life issues from Spanish language station, Radio Bilingue; increasing referrals from agencies like Salud Para La Gente and La Familia Center; legislation that extended Medicare and Medicaid to coverage of hospice care; and word of mouth by families like the Zárates.

"I tell people I meet who might be able to use help 'Accept this' help. We too had doubts and fears, but it was good for us," said Veronica Zárate.

Looking for guidance, Hobson called other Hospices around the country. It quickly became clear that everyone was asking the same questions: If the need is so big, why aren't Spanish speakers coming in? What are the barriers? What is the role of the church in end-of-life care? How do we recruit and train volunteers? Is fear of death different in Spanish culture? How do we serve those with compounded losses: The many who have lost land and livelihood in Mexico and are now losing a loved one?

Working with Hospice Caring Project's bereavement director Charmiel Teresi, local social service and counseling agencies serving Spanish speakers and Hospice professionals from around the state, Hobson organized next month's conference for Hospice workers. "The Challenge of Change: Effectively Serving Latino Communities" hosts speakers coming from the

National Resource Center on Diversity in End-of-Life Care in Washington D.C. to Barrios Unidos in Santa Cruz.

Subtle differences

"People grieve in their native tongue," said Teresi, who came to Santa Cruz after 17 years at the Center for Living with Dying in Santa Clara County. "In making Hospice more accessible, we're finding that we can't expect the way we've been doing things to work for everyone."

While language difference is the main barrier for many immigrants, there are more subtle differences, as well as misunderstandings, that stand between those in need and the agencies that aspire to serve them.

Because Hobson's clients are not comfortable coming into an office to talk about their grief, he does his work — listening, talking, eating — in driveways, living rooms and kitchens around the county.

Religious faith as well may be an obstacle to seeking the help of Hospice.

"Typically Latinos don't want to admit that someone is dying," he said. "They don't want to give up on the possibility of a miracle."

Carmen Robles is the director of the long-term care integration project at the Health Services Agency of Santa Cruz

County. She is also one of the speakers at the upcoming conference.

In her experience as a cultural worker, Robles found that cultural differences require a completely different mind set — from more time allotted for intake to adjusting to the different needs of a large extended family.

Marc Breindel, who coordinated "Ultimos Cuidados" at Radio Bilingue is reluctant to label differences in Hospice needs as cultural.

"I think the differences are more practical than anything," he said. "Like language and knowing where to do outreach."

"But death is universal. When you're mom is dying, your mom is dying."

Still remembered

When Jose Zárate Martinez died at home in early January of 2001, his whole family was with him. He was 55 years old.

with love," Veronica remembered, tears washing her high cheeks while her daughter stroked her hair.

For the Zárates, Jose may be gone but his life continues in words and the love they feel for their mother, Gema.

Hospice care doesn't end with the death of the loved one, and nearly three years later, Bruce Hobson continues to drop in on the Zárates to hear again the story of the father who gave his children sound advice and listened to his beloved music — "¡Echale canciones! (Put on the music)" he'd say — up to the day he died.

"I still cry every time I talk about him because I still miss him so much," Veronica said. "But little by little I get more courage."

Bilingual? Hospice Caring Project needs Spanish-speaking volunteers. Call 688-7684, ask for Charmiel or Bruce.

Contact Nancy Redwine at andremore@san-cruz.com.