

FEATURES

When to say, 'enough is enough'

For terminally ill cancer patients, choosing hospice care over aggressive treatment can often help prolong life and ease suffering

BY JANE E. BRODY
NY TIMES NEWS SERVICE, NEW YORK

Thirty years ago Forbes Hill of Brooklyn, New York, learned he had prostate cancer. At age 50, with a young wife and a fear of the common side effects of treatment — incontinence and impotence — he chose what oncologists call “watchful waiting.” For 12 years, Hill was fine. Then in 1990 his PSA count, a measure of cancer activity, began to rise, and he had radiation therapy. That dropped the count to near zero. In 2000, with the count up again, he chose hormone therapy, which worked for a while.

Three years ago, with his PSA level going through the roof, he learned that the cancer had spread to his bones and liver. It was time for chemotherapy, which Hill said he knew could not cure him but might slow the cancer's progress and prolong his life.

His oncologist was candid but not very specific. His doctor told him that with advanced metastatic hormone-resistant cancer like his, 90 percent of patients die within five years no matter what the doctors do, and about 10 percent survive six or more years.

“I took that kind of hard,” said Hill, an associate professor of media studies at Queens College. “I always thought I would live to 90, but I guess now I won't.”

He has just started radiation to the brain, perhaps with infusions of an experimental drug afterward. “I'll try chemo for six months, but if it gets too uncomfortable and inconvenient ...” he said, trailing off. “Having lived 80 years, I've done a lot. I don't have reason to think I've been badly treated by life.”

Hill seems ready for a time when treating his cancer is no longer the right approach, replaced instead by a focus on preparing for the end of his life.

But doctors who have studied patients like Hill say often they do not know when to say enough is enough. In a desperate effort to live a month, a week, even a day longer, they choose to continue costly, toxic treatments and deny themselves and their families the comfort care that hospice can provide.

TOUGH DECISIONS

Specialists in ovarian cancer from University Hospitals Case Medical

Center in Cleveland described a study of 113 patients with ovarian cancer in the journal *Cancer* in March.

“Patients with a shorter survival time,” they found, “had a trend toward increased chemotherapy during their last three months of life and had increased overall aggressiveness of care but did not have improvement in survival.”

The team concluded, “Our findings suggest that in the presence of rapidly progressive disease, aggressive care measures like new chemotherapy regimens within the last month of life and the administration of chemotherapy within the last two weeks of life are not associated with a survival benefit.”

With aggressive therapy, the majority of the women in the study who died did so without the benefit of hospice.

Thomas J. Smith, an oncologist and palliative care specialist at the Massey Cancer Center of Virginia Commonwealth University, said in an interview that patients needed to understand the trade-offs of treatment.

“Palliative chemotherapy, which is what most oncologists do, is meant to shrink cancer and improve the quality and quantity of life for as long as possible without making patients too sick in the bargain,” he said.

The Cleveland team pointed out that the treatment goal can, and should, change. “There is a difference between palliative chemotherapy administered early in the trajectory of disease and near the end of life,” the researchers wrote. “The goal of end-of-life care should be to avoid interventions, such as cytotoxic chemotherapy, that are likely to decrease the quality of life while failing to increase survival.”

In fact, those who choose hospice over aggressive treatment often live longer and with less discomfort because the ill effects of chemotherapy can hasten death, Smith wrote in a review of the role of chemotherapy at the end of life, published in June in *The Journal of the American Medical Association*.

Some patients are just unwilling to acknowledge that nothing can save them, and want toxic



GRAPHIC: TAIPEI TIMES

treatment even if it means only one more day of life.

And sometimes patients are reluctant to relinquish treatment because they are terribly afraid of dying, of being alone cut off from care, Smith said in the interview. Patients may fear, with some justification, that if treatment stops the doctor will abandon them.

It is not only patients and their families who may insist on pursuing active treatment to the bitter end. Sometimes, doctors subtly or overtly encourage it. Oncologists may be reluctant to acknowledge that they can no longer sustain a patient. They may fear destroying a patient's hope. Or they may be covertly influenced by the fact that their income comes from treatment, not from long discussions with

patients and families about why palliative therapy should yield to supportive care.

Smith says cancer treatments in the US “have a huge price tag of up to US\$100,000 a patient per year,” which can impoverish even insured patients when there is a 20-percent co-pay.

He urges doctors to talk about hospice early, while treatment options are still available, and to assure patients they will not be abandoned in hospice.

SWITCHING TO COMFORT CARE

While there is no official definition of futile care, Smith suggests that it represents care that is “very unlikely to help and likely to harm.”

The National Comprehensive

Cancer Network has established some guidelines about when to switch to comfort care. They vary according to the type of cancer and nature of available treatments, but in general they include when a patient has already been through three lines of chemotherapy or when their performance status — how well they can function in daily life — is poor.

Smith said most chemotherapy regimens had been tested only in patients who are relatively well, independently mobile and able to perform most of the tasks of daily life.

For those who are confined to a bed or a chair for half or more of the day, “it is time to think long and hard about continuing treatment,” he said. “It's time to have an extensive discussion with patients

about their goals and the risks and benefits of chemotherapy.”

He suggested that doctors “put everything in writing — here's what you have, what we can do for it, what will happen with treatment and without it — so that everyone is on the same page,” eliminating the risk that wishful thinking colors what patients hear.

When faced with a patient who says, “I'll do anything to live two minutes longer,” Smith said the doctor should ask: “What is your understanding of your illness? What would you like to do with the time remaining?”

For most people, he added, the time left would be far better spent putting their affairs in order, preparing their funeral or memorial service, repairing damaged relationships, leaving lasting

legacies and saying their goodbyes.

QUESTIONS PATIENTS SHOULD ASK

Patients armed with clear-cut facts are often able to make wiser choices about their care. Yet doctors are often reluctant to broach these matters.

In their review in *The Journal of the American Medical Association* of the role of chemotherapy at the end of life, Thomas J. Smith and Sarah Elizabeth Harrington listed these questions to ask — of professionals and of yourself — when considering chemotherapy that is unlikely to cure the cancer but may extend the length and quality of life.

Treatment and Prognosis:

- What is my chance of cure?
- What is the chance that this chemotherapy will make my cancer shrink? Stay stable? Grow?
- If I cannot be cured, will I live longer with chemotherapy? How much longer?
- What are the main side effects of the chemotherapy?
- Will I feel better or worse?
- Are there other options, like hospice or palliative care?
- How do other people make these decisions?
- Are there clinical trials available? What are the benefits? Am I eligible? What is needed to enroll?
- What are the likely things that will happen to me?
- How long will I live? (Ask for a range, and the most likely scenario for the period ahead, and when death might be expected.)

Planning:

- Are there other things I should be doing?
- Should I prepare a will?
- Do I have an advance directive?
- Have I assigned a durable power of attorney for health care?
- Are there financial or family legal issues that should be addressed?
- Do I need a durable power of attorney for financial affairs?
- Should I be setting up a trust?
- Family issues: Will you help me talk with my children?
- Spiritual and psychological issues: Who can help me cope?
- Legacy and life review: What do I want to pass on to my family to tell them about my life?

[SOCIETY]

Meet the Brzozowskis: Hoklo speakers with their own TV show

BY DAN BLOOM
CONTRIBUTING REPORTER

Most expats in Taiwan have a pretty hard time mastering Mandarin, although with time and effort it can be done. Many foreign residents do succeed at it, and some have even learned to write in Chinese, publishing newspaper articles and books in Mandarin.

But learning to speak in Taiwanese — fluently — is a horse of a different color. Meet Jason Brzozowski (白毅明) and his brother Jared (白念祖).

Jason Brzozowski was born in Kaohsiung, the son of American missionary parents who first came here in 1981, and he has resided in Taiwan, off and on, for around 18 years.

He and his elder brother now appear regularly on a cable TV show called *Zaidi Yingwen* (在地英文), where the entire six-person cast speaks Hoklo (commonly known as “Taiwanese”), English — and very little Mandarin. The show, which hit the airwaves in January, runs twice daily on Channel 100, according to the producers. Jared plays “Jeff” on the instructional part of the show, along with a Taiwanese teacher named “Thomas,” played by veteran actor Yong Shen-chung (楊仲崇), while Jason retains his own name for his character who portrays a houseguest staying in a local home with Ah Hong-bei (阿紅

伯) and his daughter Xiao Hong (小紅), played by actress Wu Yi-zhen (吳易嫻), 25.

When asked how he and his brother learned to speak fluent Hoklo, a feat that few foreign residents here master, Jason explained how it happened.

“I spent most my life growing up in Kaohsiung where Taiwanese is basically the local language, in addition of course to Mandarin,” he said. “Especially during childhood, when you are a kid, you learn fast. But when it came to Taiwanese, I wasn't quite as good my older brother Jared, who really picked it up fast and naturally, much faster than I did. He's the only American in Taiwan, to my knowledge, who can speak Taiwanese as well as the local people.”

To illustrate his brother's proficiency in Hoklo, Jason tells a story: “I remember one time when Jared was talking to some friends in Taiwanese while walking into a convenience store, and a local taxi driver overheard my brother speaking fluent Taiwanese. The cabbie froze in his tracks, looked back in disbelief and muttered, ‘I must have had one too many drinks today!’”

The cable TV show, sponsored by the Presbyterian Church but without any religious content in the show itself, runs in half-hour segments. Its purpose is to teach English to Taiwanese people.



Brzozowski said he heard that the show is being aired in Los Angeles now, too, where some Americans are watching the show to learn Hoklo. Although this was not the original intention of the program, the producers are delighted it has been picked up in a novel way by US viewers.

Jason noted that three years ago his Hoklo proficiency was not up to snuff, especially compared with his elder brother's fluency. But when he was asked to appear on the *Zaidi Yingwen* show, the director, Ah Pao (阿炮), who plays the father in the cast, pushed him to learn Hoklo better.

“Tsai Ming-yi (蔡明毅) is Ah Pao's real name,” Jason added, noting that he's been a TV actor for almost 20 years.

“Ah Pao was the spark who turned me into a more or less fluent Taiwanese speaker,” Jason said. “In the beginning of the show, I had to learn and memorize my lines in Taiwanese, and it was not easy at first. But after three months of training by Ah Pao, I did it.”

When asked how the unique TV show came into being, Jason said that New Eyes Television (www.netv.org.tw) got the show off the ground on cable.

“It was Chen Tien-le's (陳天樂) idea, and he played an important role in putting things together during the beginning stages of NETV, and at the same time he was trying to think of a good way to promote the Hoklo language on television. His idea was that



Jason Brzozowski, far left and above, center, co-stars with his brother Jared in *Zaidi Yingwen*, which aims to teach English to Taiwanese. PHOTOS COURTESY OF JASON BRZOZOWSKI

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— Jason Brzozowski

if viewers could see foreigners speaking fluent Hoklo, this might encourage local people here to better appreciate the language, and might even help some Taiwanese to want to brush up on their own

Hoklo skills. And, at the same time, of course, it would be a wonderful way to help people learn English as well.”

Brzozowski also credits Wang Shu-wei (王旭暉), the producer of the show and now vice-president for programming at the cable TV outlet in Taipei, as being part of the brains behind the show, which began airing nationwide this January.

In addition to Jason and his brother Jared, the cast also includes longtime Tainan resident David Alexander, who teaches theology at Tainan Theological College, a Presbyterian school.

“David, who is called Ya Da-wei (亞大偉牧師) on our show, has been in Taiwan for over 25 years, and he speaks Taiwanese like a pro,” Jason noted. “In fact, he speaks more Taiwanese than [Mandarin].”

And there's a girl in the show, too. According to the show's backstory, the character Xiao Hong, a young Taiwanese woman, became acquainted with “Jason” when she went to study English in the US. When she returns to Taiwan, she invites Jason to visit her home. The show takes place in her father's house, most of the time, with some location filming outside the studio as well.

The show is filmed inside at NETV's state-of-the-art Taipei studio. “The studio started out in the basement of an old unused

church building, but now we have a new studio, which is the headquarters for NETV,” Jason said. “In the beginning, when we first started making the show, we worked from 8am to as late as midnight sometimes, completing in one day, at most, maybe just two 30-minute shows. But, as things progressed, we can now make two or three a day in an 11-hour shift.”

Jason, who is based in Kaohsiung, travels to Taipei a few times each month for the studio work. However, the other cast members, who work in the instructional parts of the show, have different schedules, he noted, adding: “In the end, though, the final result is a very well-made cable show, and it's gaining popularity with both locals and expats around the island.”

Brzozowski, who says he has plans to write a book one day about his life in Taiwan, is now in the process of putting together a new TV show for NETV, to be called *Jason Xinfu Beibaoke* (幸福背包客) (“Jason, the Blessed Traveler-Backpacker”).

“We've already shot two shows, but we have another 11 to go before the station can begin to air it as a series,” he said. “It will allow Taiwanese viewers to see how a foreigner like me travels, plays and mingles with the local people here, and we're having fun filming it.”