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The Diagnosis Dilemma

BY MARC SILVER

To tell or not to tell?

In February 2007 Roz Zakheim learned she had non-Hodgkin's lymphoma. The Los Angeles lawyer told her husband, her son, her friends, and her coworkers. But she didn't tell her 91-year-old mother. "I'm the person primarily responsible for her," Zakheim says. "I was just so worried about how devastating it would be to her."

Many cancer patients wrestle with the question, should I tell? And if so, whom to tell? Cancer experts believe most people join the candid cancer crowd.

"I told everybody right away," says Hester Hill Schnipper, chief of oncology social work at Beth Israel Deaconess Medical Center in Boston, who has twice been diagnosed with breast cancer. "I'm one of those people who had trouble not telling the person in the checkout line at the grocery store." She is a fan of disclosure: "I think it's cathartic, a way of starting to own it. Every time you say it aloud, it's a little more real."

Then there are the selective tellers, like Zakheim. Some keep news of a cancer diagnosis from elderly or emotionally frail relatives. Others inform virtually no one—perhaps just a few members of their inner circle.

"When I was a young eager beaver social worker, I would have thought there was never a reason not to tell," says Schnipper. Now she understands the impulse to cover up. "I've changed my opinion. Sometimes the right decision is not telling your 90-year-old mother in a nursing home in Florida." Nonetheless, in cancer circles, honesty is usually regarded as the best policy.

Why They Conceal

Cultural influences keep some people from sharing their diagnosis. Among Hindu religionists, cancer is often viewed as karmic payback for bad deeds from a past life, says Zul Surani, a community health educator who co-founded Saath, a nonprofit group that has a program to assist South Asian cancer patients. "One of our survivors said people in her religious community were telling others, 'Stay away even from her shadow, because she'll bring you bad luck,'" says Surani.

The Latino community, by contrast, has a tendency to get the whole family involved in supporting a cancer patient, says Amelie Ramirez, director of the Institute for Health Promotion Research at the University of Texas Health Science

Center at San Antonio. But she also sees stoic Latinos who think they can handle it on their own.

A fatalistic streak about cancer seals many lips. “In the Chinese community, people still think, ‘There’s nothing I can do about cancer, I will die soon,’ ” says Evaon Wong-Kim, PhD, a professor of social work at California State University, East Bay. Such a patient may not want to burden children, or even a spouse, with a cancer diagnosis. Yet this is hardly a Chinese-only viewpoint, Wong-Kim is quick to point out. Such feelings can be found in virtually every community, from African-American to white Anglo-Saxon Protestant, particularly among older generations.

And in every community, cancer patients make decisions based on their own personality and the personalities of their family members and friends. Louise Scott, 47, of Little Rock, Arkansas, told lots of people about her diagnosis of colon cancer but didn’t bring certain out-of-town buddies into the loop for a few months.

“I had close friends who were all problem-solvers,” she says. “They would have been giving me advice.” That’s not what she wanted: “I needed to figure it out myself.”

☒ Crises can bring out the best in people. If you don't clue someone in, you don't give them the occasion to rise to the occasion. ☒

—Anne Coscarelli, PhD

If the disease is in a watch-and-wait stage, not telling doesn’t require elaborate deceptions. Diagnosed with smoldering myeloma eight years ago, Susan goes in for regular blood tests to monitor her condition, considered a precursor of active disease. But she shows no symptoms. The 56-year-old New Yorker asked that her last name not be used because she has confided in her husband, a few close friends, and that’s it. Her mother, siblings, and grown children have no clue. “I feel like my children have enough pressure in their lives,” she says. “They’d be nicer to me if I tell them, but they’re treating me like regular, and that’s good. I don’t want them to feel sorry for me or to worry.”

Late-stage disease may also prompt a degree of silence. Robin Baird practically made a public announcement when she was diagnosed with breast cancer in 2001 at age 43. The cancer has since recurred as metastatic disease. “I’ve never hidden it but I’ve told fewer people,” she says, “mostly because I don’t like the reaction. When you’ve had cancer multiple times, people do start looking at you like you are going to die. And I’m still Robin. I’m not cancer.”

☒

Roz Zakheim kept her cancer diagnosis from her elderly mother for seven months. Photo by Michael Kitada

The Cost of Secrecy

The decision to conceal can bring its own set of problems. Relationships may be adversely affected, says psychologist Anne Coscarelli, PhD, director of the Simms/Mann-UCLA Center for Integrative Oncology at the university's Jonsson Comprehensive Cancer Center. "You're not acting authentically because you're so afraid of it being revealed. It affects the relationship in a negative way—it's not one heart to another heart."

Children who hear about a parent's cancer from a source other than the parent, she notes, may feel they can no longer trust mom or dad. As for withholding the information from relatives who may seem too weak to cope, Coscarelli advises, "Crises can bring out the best in people. If you don't clue someone in, you don't give them a chance to rise to the occasion."

As for swearing a few close family members or friends to secrecy, well, good luck with that. "Everyone you tell is going to tell someone else," says Shirley Otis-Green, an oncology social worker at City of Hope Medical Center in Duarte, California. "They're going to tell a confidante. They're not betraying you. That's what social beings do."

Family members who do manage to keep the diagnosis in the closet may themselves suffer as a result of their silence. Jackie Schmidt's father was diagnosed with prostate cancer in 1995 and died of the disease in 1998. He told only his wife, his two children and their spouses, and, near the end, a few close friends.

"It was very important to him to pretend it wasn't there," Schmidt says. "He wanted to live as normally as possible." His decision saved his family the effort of explaining to people how he was doing, but there were significant trade-offs.

"All the support for my dad was left on the shoulders of our small family," Schmidt explains. "My mom could have had more shoulders to lean on as a caregiver than she did. But that was the way my dad wanted to do it. We all had to respect that wish."

Do Cover-Ups Work?

Many selective tellers are happy they zipped their lips. Freelance consultant Karl, who's 58 and requested anonymity, doesn't want his clients to know he has Waldenström macroglobulinemia, a rare, low-grade form of non-Hodgkin's lymphoma that's similar to multiple myeloma. His only symptoms have been fatigue and headaches; he has not had to undergo treatment.

"No one can look at me and see anything," he says. So his clients are not in the loop, even folks he's known for years. "They would assume I couldn't do the work," he explains. "And I can do the work." He also has shielded his elderly mother from the information, figuring she would just sit around and worry. The only tension comes when she gets together with other relatives who do know.

He felt his decision was justified when his brother was diagnosed with

Parkinson's disease. His mother's reaction: "Thank God it's not cancer."

Other times, a no-teller becomes a teller, and that's not such a bad thing.

After seven months of keeping her lymphoma diagnosis a secret from her mother, Roz Zakheim decided to reveal the news. "I was using a lot of emotional energy not telling her," she says. "I finally realized maybe it was better if I did tell her." She had cut back on visits to her mother because of the burden of concealment, and she couldn't truthfully explain why she was sometimes cranky or tired.

Zakheim broke the news in a restaurant, hoping a public setting might prevent any meltdowns. She didn't use the "c" word but described a lump that had been found that wasn't benign, her radiation treatment, and her doctor's optimistic outlook. Her mother simply said, "I hope it doesn't come back."

Now Zakheim visits her mother more frequently, and as for fears that her elderly mother would feel helpless, they didn't prove true. Zakheim's mother came up with a way to offer support, telling her daughter, "I pray for you every night." The relationship between the 91-year-old mother and the 60-year-old cancer survivor has never been better.