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## cover story

### Stressed families

A 2004 study led by Anne E. Kazak and colleagues at the Children's Hospital of Philadelphia and published in the *Journal of Pediatric Psychology* looked for post-traumatic stress in 150 families with a child who completed cancer treatment an average of five years earlier. Nearly all had at least one parent experiencing some symptoms, if not the more severe post-traumatic stress disorder (or PTSD).

18.8%  
PTSD

69.1%  
Arousal, or general anxiety

40.9%  
Prone to avoiding the topic

98.7%  
Stress triggered by reminders  
(called reexperiencing)



Colleen and Ryan Tierney were fearful of the toxicity of the chemotherapy their baby daughter Chloe was receiving for treatment of

# WHEN HEALING HURTS

As a child undergoes treatments for a serious illness, parents may suffer, too — with fear, guilt, and depression

By Chelsea Conaboy  
GLOBE STAFF

**D**ays after she was born, Chloe Tierney was diagnosed with a rare brain tumor. Her parents, Colleen and Ryan, never considered doing anything less than everything they could to help her.

Yet, as Chloe started the chemotherapy that doctors at the Floating Hospital for Children at Tufts Medical Center had prescribed, the parents found themselves fearful not just of the disease but of the treatment, too.

During pregnancy, Colleen Tierney, 28,

said, "I was so careful eating and doing everything right, and now, I'm going to put poison into my child?"

The same protective instinct that drives parents to go to war against cancer can make the battles faced in treatment especially hard.

For some parents, clipping a baby's fingernails for the first time can be difficult. Watching them get their first shots — excruciating. When cancer hits, parents must agree to treatment that often leaves their child weak, lethargic, bald, bloated, nauseous, and in pain.

Last month, Kristen LaBrie of Beverly was found guilty of attempted murder for

failing to give her son, Jeremy Fraser, drugs prescribed to help him fight a highly curable non-Hodgkins lymphoma. Jeremy, who was autistic, was removed from her custody in 2008; he died the next year at age 9. Prosecutors said LaBrie's actions amounted to abuse.

LaBrie's case was extreme. But a comment she made on the stand resonated with some parents whose kids have faced cancer: In her mind, the treatment had become a bigger villain than the disease.

While the desire to beat cancer wins out in the overwhelming majority of cases, specialists interviewed for this story — none of whom wanted to comment on the

LaBrie case directly — said many parents feel guilt and fear about the impact of onerous treatments. Coping with those feelings during diagnosis and prolonged treatment can require the support of a team of oncologists, psychologists, therapists, nurses, and others.

"Every time you sign on the dotted line for your child to have a procedure, you are having to read, 'They could die. They could die. They could die,'" said Priscilla Grippi, a parent consultant and advocate in the oncology department at the Floating Hospital.

She knows firsthand what that burden is like.





JOHN TLUMACKI/GLOBE STAFF

a brain tumor.

In 1986, Grippi's 11-year-old son, Peter, was diagnosed with leukemia. He regularly underwent a painful procedure to look for leukemia cells in his bone marrow, a process that newer drugs have since made easier.

Grippi recalled that Peter told her once as they drove to the hospital, "Mom, if you do this to me and I die, I'm never going to forgive you."

Within months, he was gone.

"You don't have a crystal ball," she said.

Two years after her son's death, Grippi began working as an advocate for other families at the Floating Hospital. She is an all-around problem solver, holding hands, answering questions, helping families apply for assistance programs, and writing letters to utility companies asking them to keep the power on despite unpaid bills.

Every case is different, Grippi said. Prognosis, treatment options, and the ability of children to participate in decisions about their care shape how families react.

"There's a lot of initial distress related to the diagnosis," said Lamia P. Barakat, director of psychosocial services at the Children's Hospital of Philadelphia. "For most families, that initial distress dissipates."

Many parents report that beginning treatment is reassuring because they know they are taking action against the cancer, she said. For those who feel sustained guilt, Barakat said she tries to help them reframe it by identifying what parenting strengths they possess that can help their child cope.

In recent years, researchers and clinicians have begun evaluating family members based on their risk for developing post-traumatic stress. Despite drugs that can alleviate side effects of powerful cancer drugs and the many ways that a hospital can support a family through treatment, the likelihood that a child will suffer some on the treatment path is high, said Dr. Cathy Rosenfield, clinical director of pediatric oncology and hematology at the Floating Hospital.

"Every parent hopes that their child is going to be cured," she said. "In the process of going through that treatment, you have to hold tightly to that hope. If you don't, then it makes the treatment impossible to bear."

Good communication is key, Rosenfield and others said. Families require early and frequent conversations about how the treatment is progressing, what to expect, how the child is faring, and what resources the hospital can provide.

Families "bring to the table the way in which they functioned as a family to begin with," said Dr. Joanne Wolfe, oncologist and director of pediatric palliative care at Children's Hospital Boston.

Their decisions about care might be influenced by big problems aside from the cancer, such as conflict between parents, financial troubles, or a preexisting medical condition within the family. Small things matter, too.

Children who don't like swallowing pills, for example, might fight for hours each day when a parent administers their required medications. That can be disruptive to family life, said Dr. Anne Reilly, medical director of oncology at Children's in Philadelphia. A therapist can help remove that obstacle to care by teaching the child to take medications, practicing with

ice cream sprinkles and M&Ms and working up to the size of the pills.

Physicians assume that parents know their children best and they take guidance from them about how much a child can handle, Wolfe said. But occasionally doctors and families cannot come to a consensus about the best course of care, she said. When that happens — about once a year in her practice — Wolfe said physicians call on hospital ethics boards and social workers to help sort it out. Sometimes it becomes clear that parents do not have the best interest of their child in mind, she said, but those cases are rare.

"The vast majority of families who face extraordinary circumstances because their child is ill really are able to come together and make, together with health care teams, the best decisions for their children," she said.

Wolfe said the opposite situation is challenging, as well: families that are willing to go through whatever is necessary, no matter how difficult, to give their child a chance at beating cancer. Particularly when the prognosis is poor, she said, balancing that desire for aggressive treatment and the quality of a child's life is difficult, she said.

Tierney said she thinks two things made it easier for her family to get through treatment for her daughter. Unlike with Grippi's son, Chloe, who is now 1 and tumor-free, was too young to protest her treatment. And, Tierney said, it helped that Chloe was treated while admitted to the hospital. The Tierneys never had to administer the drugs themselves.

"I definitely would have done it," she said. "But it would have been awful for me to have to give it to her and then see how sick it made her."

Grippi and Tierney said that they reserve judgment on LaBrie.

"You ache for that mom," Grippi said. "I don't know how she's going to forgive herself for this."

Chelsea Conaboy can be reached at [cconaboy@boston.com](mailto:cconaboy@boston.com).



PAT GREENHOUSE/GLOBE STAFF

Priscilla Grippi (right), a parent consultant at the Floating Hospital for Children, talks with Rebecca Morrow, the mother of a teen patient.

## Illness and PTSD

A diagnosis of childhood cancer changes a family forever. Researchers have begun evaluating whether family members develop symptoms of post-traumatic stress.

In a 2004 study published in the *Journal of Pediatric Psychology*, Anne E. Kazak and colleagues at the Children's Hospital of Philadelphia looked at 150 families who were, on average, about five years out from treatment. Nearly all had at least one parent with symptoms of post-traumatic stress, such as feeling anxiety when they see a TV ad for a cancer center or returning to the hospital for follow-ups. Some avoided talking about the issue or experienced a generally elevated level of anxiety. Twenty-eight families had a parent with the more severe post-traumatic stress disorder, or PTSD.

Now some of the same researchers are developing a tool to evaluate family members at diagnosis with the goal of figuring out which ones may be at risk for developing PTSD, and connecting them with resources and help. The assessment considers family members' financial stability, level of trust in medicine, beliefs about cancer, pre-existing medical conditions, network of social support, and emotional problems. The tool is being used at various cancer centers around the country.

"If even one person is experiencing symptoms of post-traumatic stress, it's going to affect how the family is functioning on a day-to-day basis and around cancer and cancer care," said Lamia Barakat, director of psychosocial services in the pediatric oncology department at Children's Hospital of Philadelphia and an author on a study published this month in the *Journal of Pediatric Hematology and Oncology* about the assessment tool.

Rebecca Morrow, 43, understands how a cancer diagnosis can have long-term effects. The Billerica mother couldn't eat or sleep after her 14-year-old daughter, Shelby, was diagnosed with acute myeloid leukemia in March and then developed an infection that landed her in intensive care. Morrow said she began having panic attacks.

"You just have all these emotions, and you don't know where to put it," she said. As her daughter began treatment, the family settled into a routine. But, Morrow said, it's still hard. "As a mother, it is the worst thing you could ever imagine going through. It is horrible... We'll be different people coming out of this."

Building on a concept first described in breast cancer survivors, researchers have also been looking at "post-traumatic growth" in families affected by childhood cancer.

Barakat led a 2006 study of 150 families who were at least one year out from treatment. About half of mothers and one-quarter of fathers reported positive effects on their self-perception and their relationship with family members or others.

CHELSEA CONABOY