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## Containing the pain: Youth use photovoice to capture their experiences

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Christine Junge on July 22, 2016

If you've ever been in extreme or extended pain, you know how difficult it can be to put the experience in words. How then can doctors and pain psychologists understand what their patients are going through? And how can patients get the relief and connection that comes from articulating their experience?

These were questions [Anya Griffin](#), PhD, a pediatric psychologist and clinical director of the [Pediatric Rehabilitation Program](#) (PReP) at Lucile Packard Children's Hospital

Stanford, asked herself: “Pain is one of those things you can’t see, so how can we understand the lived experience of children with chronic pain? And how can we know how effective the program is?”

PREP is “an intensive day treatment program for kids who are compromised by chronic pain. They’re not going to school, not getting out of bed. Typical outpatient care is no longer effective,” Griffin said. About three children participate in the program at a time, doing various types of physical and psychological therapies and going to a school based at the hospital.



To understand how well it is working, Griffin and her team collect patient and parent outcome measures before, during, and after the program. Although these measures are critical for tracking important patient outcomes, questionnaires in general cannot capture the complete scope of how pain affects a child’s life, Griffin said. This problem got Griffin thinking of a qualitative research method often used within public health known as **photovoice**. In this version of photovoice, made possible with support from Stanford’s **Medicine and the Muse Program**, patients take a photograph that depicts how they feel about their pain at the beginning of the program, which lasts anywhere from 3 weeks to 3 months, depending on the diagnosis and treatment needs. Then, the patients take another picture that describes how they felt about pain at the end.

“A lot of [the patients] said this is the one way they could tell people what their pain is like,” Griffin said.

The pairs of photos and their captions were hung in a display case in the basement hallway of the hospital. One set of photos showed pieces of blue, broken glass laid out on a table in the “before” picture, and, in the “after” photo, those same pieces of glass contained in a glass jar. The caption explained that the broken glass symbolizes both that the pain felt by the photographer was sharp, and that she felt broken as a person at that point. Then, at the end of the program, she had learned how to both contain her pain and how to take those broken pieces and make them into something better.

That artist, a teenager whom we’ll refer to as “Jane,” spoke at the opening of the photovoice exhibit recently. (The exhibit recently closed). She said that so much had changed from the beginning of the program to the end, everything from how she felt to how she acted to how she looked. She said that when she first started PReP, she was in a wheelchair and had braces on various parts of her body because of the severe pain; her mother added that her hair was dyed a cherry red “as if her anger were coming out her hair.” At the opening, a beautiful, energetic blond teen dressed in a maroon cocktail dress and heels stood before the room. She is now a happy, active student who is back playing the sports she once loved.

Jane now keeps a copy of the pictures she took on her nightstand at home. She said that, “when I wake up and see them, they remind me that today is going to be a good day. And even if something goes wrong that day, I know how to fix it.”

*Jane agreed to have certain details of her condition shared in this post.*

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Photo by Jane



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