

g

LIVING

POP MUSIC
CD REVIEWS OF
MARTINA MCBRIDE,
EMA, AND OTHERS
PAGE 5

BOOKS
'LONELINESS' SHOWS
MARINA KEEGAN'S
TALENT, AND TRAGEDY
PAGE 6

POP MUSIC
OVER 40 YEARS IN,
MAX CREEK KEEPS
JAMMING, GROWING
PAGE 8



MOVIES
TY BURR RECALLS
THE EPIC CAREER
OF MICKEY ROONEY
PAGE 3

Where does it hurt?

I was diagnosed

I hung up the phone

I started a regimen

I worry

I wish

I shower

I am trying

I was lucky

A multimedia art project explores the health care system through the voices and words of patients, loved ones, and professionals

BY CATE MCQUAID | PAGE 12

cover story

Human side of health care

A man whose elderly father fell and was wrongly diagnosed with an ear infection. Parents of an infant with acid reflux. A nurse who takes the time to listen to the dying sort through their relationships.

These are some of the stories featured in Patient Translations, an ongoing project created by Boston-area artists Kelly Sherman and Halsey Burgund that collects tales of the health care system and blends them into audio collage and telling snippets of text, empowering patients and their loved ones to share experiences of waiting rooms, diagnoses, and insurance companies.

The project is being publicly displayed as an installation at health care conferences but is available online for anyone to listen to or contribute a story; there are about 300 clips in the collage thus far. (See accompanying box, Page 14.)

Kate Desjardins's brother was diagnosed with Hodgkins lymphoma 2½ years ago when he was 24. Since then, he has had two stem cell transplants.

"It's grueling for everybody," says Desjardins, a middle school teacher from Bedford. "We trust the doctors, but we have to negotiate the medical system, which is not always the kindest thing."

Burgund interviewed her for Patient Translations, and her voice is woven into the audio collage.

"There's no other outlet anywhere for such a thing," Desjardins says of sharing her story. "Especially for someone like me, who is just the sister."

Often, the patient's loved ones are the people navigating the system.

"I witness the inhumanity.

Multimedia artwork blends with words and voices of patients, loved ones, and professionals

BY CATE MCQUAID | GLOBE CORRESPONDENT



KELLY SHERMAN AND HALSEY BURGUND

A month after its premiere, Patient Translations made an appearance at a TEDMED health care conference in Washington, D.C., last April.

They send him upstairs; they send him downstairs. He's waiting an hour for one thing, and the next appointment has come up," Desjardins says. "It feels sometimes like you're screaming into a void."

Sherman was commissioned by Amy Cueva, founder and chief experience officer of Mad*Pow, a New Hampshire-based design agency that stages an annual conference on the health care experience — from the ways insurers can better serve patients to creative ways doctors can collaborate with one another.

"We wanted the voice of the patient to be heard loud and clear," says Cueva. "What motivates designers is empathy, understanding what people are going through, and the way to engage that is hearing the story from people in their own voices."

In the art world, Patient Translations fits under the umbrella of social practice art: pieces that tap into and express the concerns of a particular community. In the realm of patient advocacy, they have a predecessor in Washington, D.C.,-based artist Regina Holliday, whose "Walking Gallery" features hand-painted jackets, each emblazoned with an image about patient care, health care reform, and other health care issues.

Sherman, who was awarded the Institute of Contemporary Art's James and Audrey Foster Prize in 2006, makes text-driven art. She recruited Burgund, an artist who collects voices to synthesize into a sound collage.

"We both like going out in the world and finding things, and making art from that," Sherman says.

They started interviewing people. Then they created a portable art installation with text banners

Continued on next page

Artists Kelly Sh



WENDY MAEDA/GLOBE STAFF

an (left) and Halsey Burgund unroll panels that are part of their audio-visual-Internet project on patient interactions with the often-impersonal health care system.

Continued from preceding page
and a booth where visitors could answer questions and record their experiences. The artists edited the recordings to create an artful blend of sound and text. The audio, entwined with low-key music, often packs an emotional punch — although Burgund leavens it with participants' thoughts about how to make the system better.

Sherman's text banners feature the sparest of information: "I was diagnosed." "I hung up the phone." "I worry." Because they're so sparse, they invite viewers to pour their own stories in between the lines.

Patient Translations premiered at Mad*Pow's 2013 Healthcare Experience Design Conference last March in Boston, then traveled to the TEDMED health care conference in Washington, D.C., last April. There are plans for it to appear at Mad*Pow's newly renamed conference, HxRefactored, in Brooklyn, N.Y., in May.

"Everybody's got a story. Some don't think they do, but when given the platform, they're like, 'Well, actually . . .'" Burgund says. "A lot of it was, 'I didn't know I could talk about this.' It's kind of taboo."

Such tales are personal. But there's also something about the system itself that may have people holding their tongues.

"There's almost a passive message to being in the system," Sherman says. "You need to be accommodating. You probably don't know enough. You feel insecure, small. I find it very intimidating."

Natalie Nixon, associate professor and director of the Strategic Design MBA Program at Philadelphia University, attended the Healthcare Experience Design Conference, and, after circling the project all day, recorded her story about an illness she went through. She says sharing her story was cathartic.

"I have excellent health insurance, but one bad experience



WENDY MAEDA/GLOBE STAFF

Bergund and Sherman's hand-inked panels reflect experiences of being a patient. Bergund, a sound artist, weaves sound snippets into an audio collage that goes with the texts.

too many," she says. "The last time in my network, I was in the waiting room for an hour and 20 minutes. When I went into the exam room, the doctor had forgotten who I was, and I had to repeat it all over again. I left feeling demoralized. I didn't want to have that experience anymore."

She has since subscribed to a concierge medical service, which she's happy with. "But not everyone can afford that," she says.

Share your story

If you have a health care story you'd like to contribute to Patient Translations, or if you just want to listen to the constantly evolving audio collage, visit its website, www.patienttranslations.com. If you choose to share a story, you'll find questions to prompt you. The free iPhone app is available on iTunes; it's listed under music, and "Halsey Solutions." Contributions are anonymous. If you're recording on your iPhone, you can share your audio file on Twitter or Facebook, or e-mail it.

CATE MCQUAID

"It's a systemic issue."

Although Patient Translations is an art project, as a design professional, Nixon sees its utility. "It's incredibly user-sensitive," she says.

"I think the health care industry would utilize it. It's at a tipping point. It has enough self-awareness to realize it is chronically broken, and not just for patients. Physicians are burned out," she says. "The challenge is how would you scale something like [Patient Translations]. But there's a lot of need for it, and receptivity to try a version of it."

Burgund and Sherman have talked to hospitals and other health organizations about expanding Patient Translations. Hospitals have declined their proposals, citing various legal and public relations concerns.

"We're not health care experts. We don't have tons of connections in the area, but there's a will and desire to broaden [the project]," says Burgund.

Kate Desjardins says she thinks Patient Translations should be set up in every medical waiting room, for patients and their loved ones to listen to as well as to contribute.

"The art of it is it's this random collection of snippets, which is enthralling. It can be hard to listen to, but people who have been through hard things are comforted that it's not just them," she says.

Her brother's fight continues. "We think he's going to live," Desjardins says. "It's just endless, and he's exhausted."

Sherman and Burgund have both found themselves in tears listening to the recordings, but Sherman says she has discovered an underlying optimism to all the struggles.

"Almost everybody said they were lucky. The resiliency people have is amazing," she says. "The more devastating the story, the more positive the person was."

Cate McQuaid can be reached at catemcquaid@gmail.com.