



# Humans of the Gap: Storytelling to Improve Healthcare



Elyse Conley, MS4, David Geffen School of Medicine at UCLA

Sarah Lawrence, MD, PGY1, Mayo Clinic, Rochester, Minnesota

## HUMANS OF THE GAP

Reclaiming the healthcare narrative



In 2017, direct healthcare expenditure in the United States ranged in at more than \$10,000 per capita, more than any other country in the world. This adds up to a staggering \$3.0 trillion dollars, or 18% of GDP. But who is paying this tab? Although nearly 90% of Americans are insured and paying an average of \$440 a month for individual coverage or over \$1100 a month to insure a family of four, these same individuals are faced with an additional \$360 billion in out-of-pocket expenses each year. The steadily rising costs of health insurance, and the innumerable gaps in coverage provided by these costly plans, are leaving people in every corner of this country to grapple with a choice between accessing necessary care and keeping food on the table.

In spite of a continuous onslaught of shocking statistics, America remains a nation deeply divided over the future of healthcare. Americans increasingly self-segregate based on ideology, creating echo chambers that amplify escalating levels of anger and dissatisfaction. Humans of the Gap is an initiative founded on the idea that storytelling is a powerful tool that can bring individuals together. This initiative aims to give voice to people who have struggled to access medical care, pay their medical bills, and deal with insurance companies. Our goal is to humanize the American healthcare crisis.



**“Hi. My name is Kat Parker. I love baseball and Spring. Tornadoes freak me out, but they fascinate me at the same time. I am not that piece of paper you are looking at. This is me, the human being. This is who I am. You are telling me that you’re not going to pay for this treatment, but I need this treatment to live.”**



## Kat's Story

It was April 2019 and Kat was two months into treatment for stage IIb cervical cancer. She had been feeling increasingly sick for about a year when she passed out at work. She was rushed to the hospital where her doctors told her she had been bleeding internally and was lucky to be alive. She was so sick, she had to spend three weeks in an Oklahoma City hospital receiving life-sustaining treatments. “In the hospital, I kept thinking ‘Thank God I’ve got insurance!’ I was so thankful.” Kat had no idea that fighting for her life was not just going to be a matter of battling cancer. Every step of the way, she was going to be fighting her insurance to get access to the life-saving treatments she so desperately needed. “This has been a miserable part of my life,” says Kat. “And honestly, if cancer was the only thing I had to battle... sweet! I would be so happy right now. Because my biggest battle came with the insurance. And it is a constant battle.”

Kat’s life had become unrecognizable. She was entrenched in a war with her insurance company who refused many of the treatments she needed to fight the cancer. “It was shocking that my life had a price tag. ‘This is what your life is worth, and beyond that amount, your life is disposable.’ Even though Kat had paid for an insurance policy that was intended to cover her in case of a cancer diagnosis, Kat lost everything. Because of the side effects of her chemo and the cancer itself, she could no longer work at her job as a sommelier in an upscale Oklahoma City restaurant. She had been unable to work for the better part of a year when she renewed her insurance policy and found that the cost of her policy had increased from \$145 to \$500 a month, making it entirely unaffordable. “I couldn’t make any money. How was I supposed to pay that? But they just didn’t care”

Through the course of her treatment, Kat lost her car, then her home, and her entire life savings evaporated in no time at all. For many of her treatments, she had to rely on sponsors and charities to cover the costs. She was only able to keep a roof over her head when her friends stepped in to help her pay her rent, and she was only able to stay insured with the help of family. Even though Kat’s cancer is in remission, her battle isn’t over. Her insurance company is still holding her responsible for more than \$40 thousand in medical bills. “I thought I was covered,” she says, shaking her head, “I had no idea.” “I am not just a number. I am not just a piece of paper. This is who I am. This is my life, and I’m not ready to die.”

## Long-Term Goals

- Continue gathering stories on a small scale
- Find like-minded story-tellers who are willing to interview patients and write about what patients are facing
  - Eventually re-develop a website to begin larger-scale story collection and public engagement