



The View from the Other Side — Patients, Doctors, and the Power of a Camera

Gretchen Berland, M.D.

By the time Galen Buckwalter's physician knocked on the exam-room door, Buckwalter's video camera had been recording for nearly 40 minutes. He had booked the appointment because

his shoulders were hurting, and the camera recorded his view of the examination table, the comments he made while waiting and, eventually, a largely transactional and superficial exchange with his physician. Two weeks later, in his home, the camera would record a strikingly different take on his shoulder pain — a growing problem that, Buckwalter worried aloud, might cost him even more of his cherished independence (see sidebar, page 2534).

As an internist, I was disturbed by the contrast between those two scenes, the second revealing the depth of Buckwalter's concerns and fears, none of which were apparent during the conversation

with his doctor. In the later tape, Buckwalter's struggle is palpable. If such stark contrasts are common, how much do I really know about my own patients? Probably far less than I care to admit.

Buckwalter's videotaping of his appointment was part of a project I'd begun 9 months earlier (see video at www.nejm.org). The goal was to understand the experience of being in a wheelchair, with the help of a video camera — an approach influenced by my previous career in documentary filmmaking and by research disciplines including participant-action research, narrative medicine, and ethnography.^{1,2} I have spent 10 years giving cameras to partici-

pants and have learned much from the projects. The recorded images were often unsteady and out of focus, but the content — representing participants' own views of their experience, not mine — consistently proved interesting. I learned that participants generally need more than a few days or weeks with a video camera to record their experiences adequately; the unfurling of one's life requires time.

But the results are rich; film is a medium conducive to exploring the smallest details that make up a life. These details are often overlooked, or missed, in clinical research conducted in more traditional ways. As nuances of a patient's experience are compressed into standardized responses, statistical power is achieved, but depth is lost.

What could videotape show about experiences of disability that

The Good Patient

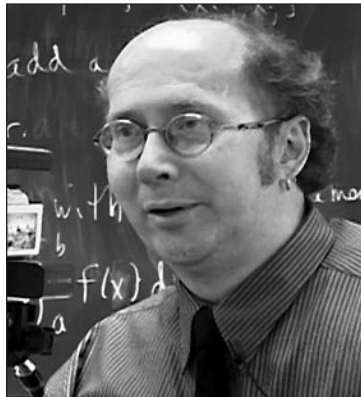
J. Galen Buckwalter, Ph.D.

The visit to my doctor was not terribly out of the ordinary. I had waited several months, hoping the pain would remit, but the throbbing in my shoulders, initially episodic and activity-related, became constant, woke me early in the morning, and made me reluctant even to try to exercise. So there I was in my doctor's office, waiting. But this time, as I waited, I talked to a digital camera I had perched on the exam table.

Every time I watch this scene, I cringe — not at the time wasted in waiting, and not even at the fact that, as I noted in the film, “it would take a hell of a gimp” to make the transfer from my wheelchair to the examining table. I do get a bit irritated when the doctor eventually waltzes into the office and, after having me reach over my head and touch the back of my head, cheerfully tells me I probably have “acromioclavicular strain.” But what makes me want to cover my eyes every time is the way I interact with my doctor. I am a professional research scientist, a member of several study sections at the National Institute of Mental Health, a vice president of a successful company that I played a pivotal role in developing. I don't consider myself brash, but I am certainly no wallflower. Yet there I am, on screen, wagging my head like a dashboard puppy. I then agree with a saying that is not only inaccurate but degrading: “Your arms are your legs, too.”

Well, my arms are not my legs.

My shoulders, however, as subsequent imaging demonstrated, are largely lacking in cartilage, and they hurt terribly. Not because they are my legs, but because I have stub-



bornly used them to push a manual wheelchair for over 30 years in my determination to live as independently as possible. Yet in the exam room, I see myself unable to communicate this problem effectively to my physician; instead, I collaborate in his avoidance of the real reasons I am there.

In looking back at that scene, I see myself in crisis. I am beginning to wonder whether I can tolerate the increase in pain. I live in a manual wheelchair, which is, in a meaningful sense, my legs. I enjoy the gentle dance of playing with gravity as I swivel down slight grades and the jarring thwack of timing the jump across a large crack in the sidewalk — every bit as much as I used to love the feel of freshly cut grass on bare toes. Yet I am aware that many people who once moved just as synchronously with their chairs now can barely get out of bed independently. Shoulder replacement may

loom, or trading the control and synergy I feel with my manual chair for the additional dependence that comes with a monstrous power chair. Coming to my doctor represents my recognition of the inevitability of another profound loss 30 years after my spinal cord injury. Though I have no illusion that anyone can relieve the emotional pain of my physical loss, the superficiality of our interaction left me alone to cope with a significant advancement in my disability. My physician's failure to study the literature on the diagnosis and management of disorders of weight-bearing shoulders delayed effective treatment; in retrospect, his response to my problem seems like incompetence. But I am convinced that if he had simply sat down, looked me in the eyes, and talked to me, he would have gained information that would have made the visit far more beneficial.

Looking at my life through a camera lens gave me a different view of my disability and my interactions with others. My zeal for objective research crumbled when I became a subject in the documentary film *Rolling* (see Berland article, page 2533). I realized I couldn't portray, much less live, my life as an object if I wanted to be engaged as a person, not a specimen or a data set.

On one level, my camera's presence gave me a currency in other people's eyes that I typically lack. Perhaps because I live in a city that values what it sees on screen above all else, when I

went out with my camera, it validated me. Suddenly, everyone wanted to know why I was so important as to be filming my life. Granted, this is not the stuff on which one wants to build a sense of self, but it beats being ignored. In addition, the camera seemed an open invitation to others' stories. Who knew so many people had spent time in wheelchairs, had a wheelchair-bound aunt, had narrowly escaped being disabled by an injury?

At another level, *Rolling* allowed me to shift from attempting to describe my experiences to showing my life to the world. And as life emerged, so did complexity; the camera became both friend and adversary. It challenged me to show something relevant, something creative — and, as in

the doctor's-office scene, revealed gaps between my implicit goals and my words and actions.

As a disabled man, I must maintain lifelong relationships with health care providers. I typically feel compelled to be the good patient, the patient to whom medical professionals will respond. Repeatedly, I have seen compliant stoicism rewarded with more time, more generous touch, more attention to my medical needs as a middle-aged, C6–C7, hypertensive quadriplegic. Expressing the emotions that accompany living with my disability evokes varied responses, but seldom has a physician responded by becoming more engaged or more determined to understand how my experience of disability can inform medical treatment. But the pro-

cess of making *Rolling* changed forever the expectations I bring to encounters with physicians.

Can video cameras help other patients make themselves known to physicians in ways that will improve the quality of health care interactions? Some of the scenes we filmed are difficult to watch, but they happen. Through them, I see what I hope will change. I have experienced what it can be like to engage with nondisabled persons without trying to anticipate what they want me to be — and such memories provide a cherished antidote to the feeling I re-experience each time I watch that doctor's visit unfold. Ultimately, at least for me, taking the camera changed the equation.

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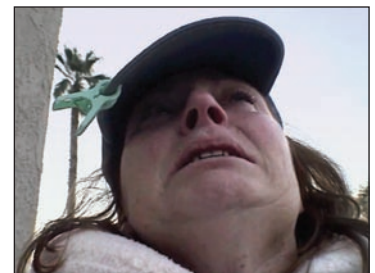
hadn't already been said eloquently in the medical literature documenting inequities faced by the disabled or in memoirs and films about being disabled?^{3,4} Perhaps a first-person perspective, recorded from the wheelchair, would reveal a world rarely seen by most nondisabled persons. Buckwalter had been the first to volunteer for the project, followed by Vicki Elman and Ernie Wallengren. All lived in the Los Angeles area and had heard about the project through the UCLA medical community. Buckwalter used a wheelchair as a result of a cervical spinal cord injury, Elman because of multiple sclerosis, and Wallengren because of amyotrophic lateral sclerosis.

They began by filming processes related to activities of daily life — buttoning a shirt with an antique bootlace hook, using

a grabber to retrieve a bottle cap from the floor. Wallengren's footage of the preparation of his breakfast drink puts the viewer in his wheelchair; we see his hand falter as he lifts the milk from refrigerator to counter. The participants filmed events related to their passions: basketball, camping, disability rights, music. They filmed their loved ones. Each used the camera as a confidant; sitting alone in his bathroom, Wallengren talks about his progressive symptoms and the choices he faces.

Moments of extraordinary frustration were also recorded, a scene captured by Elman being a striking example. After 20 years of living with multiple sclerosis, Elman required a power wheelchair. One afternoon, her regular public-transportation service picked her up from an event, and during

the ride home, her wheelchair stalled inside the van. Although it's officially against the rules, most riders say that a driver will sometimes bring them into their homes. That day, however, Elman wasn't so lucky. The driver parked



her 10 ft from her front door, where she stayed and waited. But she had brought the video camera.

The first time I screened this tape, I was horrified. I watched Elman try to call for help on a cell phone that had no signal. I watched her wait for a car to

drive by, hoping that someone would stop and help. I watched as the afternoon light faded in the background.

I wish the indignity Elman suffered that day was an isolated event, owing to one overworked bus driver. Yet the material she and Buckwalter recorded suggests otherwise. Their filmed interactions with the health care system, including telephone calls with insurance companies, visits with physicians, and exchanges with nursing aides, reveal a culture that can be both naively ignorant and, sometimes, dangerously neglectful.

Over a 2-year period, the participants recorded more than 200 hours of material. Our research team logged, transcribed, and reviewed the footage with the participants, using qualitative research methods. The sum of the recorded experiences made us realize that the strength of the project lay in the images themselves. So we began editing the footage, attempting to weave the narratives into a work that would more closely reflect the protagonists' lives. What started as "The Visual Study of Life in a Wheelchair" evolved into a film, *Rolling*.

Rolling has been shown in many venues, perhaps most memorably One World Berlin, a human-rights film festival. After one screening there, several audience members — some from the German disability community, others Berlin health care providers — approached Elman. Having seen her experiences in the United States, they had some advice: Stay here.

It was tempting to contemplate that a move might alleviate some of her problems, but Elman had

built her life in Los Angeles, not Berlin. Still, I savored that moment, because other viewers were less sympathetic, convinced that the responsibility for change lay



with Elman, Buckwalter, and Wallengren. At a meeting of a state medical society, a physician asked whether the participants were taking antidepressants: it might make things feel less difficult, he advised. At one screening, a medical student even inquired whether the participants had considered having their legs amputated, in order to make transfers from their wheelchairs easier.

The three participants in this project taught me to see the world in ways I had never imagined. I do not look at a sidewalk or the incline of a hill as I did before. Steps, doors, building entrances, rooms appear different. I now assess manual and power wheelchairs with a critical eye. The impact, however, is broader than that. I listen more carefully. I consider the time and effort it takes for patients to reach my clinic and how long they have waited before coming to see me with a problem.

I'd like to think we, as health care providers, begin our days with

our patients' best interests in mind. Perhaps the nursing aide who denied Vicki Elman's legitimate request to be lifted onto a bedside commode didn't understand the consequences of her refusal. Human dignity is fragile. It can be stripped away in seconds.

Perhaps what was filmed can largely be ascribed to our dysfunctional health care system. Our visits with our patients are often limited to 15 minutes. Few of us receive formal training in caring for disabled persons. But at what point do we take ownership for the segments of the health care arena in which we participate?

Recent work on the quality of care calls for creating a patient-centered health care system. But in order for it to be patient-centered, don't we need to understand patients' perspectives? Though I know it would be impossible to give every patient a video camera, wouldn't it be interesting to imagine what they might record if we did?

A video and an interview with Drs. Berland and Buckwalter are available at www.nejm.org.

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