
Storytelling About AIDS: A Duty of Care

by Robert M. Steele

Journalists are frequently challenged and criticized for poor reporting when it comes to coverage of AIDS. That indictment is not inappropriate, particularly as it applies to reporting prior to the mid-1980s. But in the past seven or eight years there has been some excellent reporting on AIDS that has informed and educated the public about the disease itself and its implications for our society. We have come to know more about AIDS through the writing and the photography of talented journalists who provide intense profiles of those struggling with the disease, of family and friends who help those with AIDS, of health professionals who give comfort. Reporting on AIDS requires storytelling excellence and it requires journalists to "care" deeply about the subjects of their stories.

As a journalism ethicist I frequently deal with case studies about the coverage of AIDS. My files are bulging with stories on the subject, as well as many articles that critique how the media has covered AIDS. Beyond that, my personal recollections on the issue of AIDS include several well-defined moments. One occurred in 1981 while I was still practicing daily journalism and beginning my Ph.D. work in ethics. I was a member of a panel of journalists and medical professionals discussing how the press reports on medicine and health policy issues. One topic of discussion was herpes, at that time a fairly big story. During a break in the sessions a physician casually mentioned that the herpes story was nothing compared to what was coming down the road. He didn't put a name on this developing medical nightmare, but the disease he described to me was Acquired Immune Deficiency Syndrome, soon to be known by its terrifying acronym—AIDS.

I made some mental notes on what the physician told me, but I didn't do much reporting on the issue. Sadly, the same can be said about how journalism in general handled the AIDS issue until the mid-1980s. It wasn't until the word epidemic was attached to AIDS, until movie star Rock Hudson died from it, until young Ryan White fought school boards because of it, until AIDS affected virtually everyone in one way or another, that the mass media really took significant notice. True, there were a few health reporters around the country who covered the story in the early 1980s (I remember some fine reporting by Laurie Garrett on National Public Radio, for instance), but AIDS remained a relatively unexplored issue.

The late Randy Shilts was an exception to the ambivalence and ignorance. He was perhaps the most famous of journalists who covered this issue. His 1987 book, *And the Band Played On: Politics, People and the AIDS Epidemic*, is among the best on the subject. And his reporting over the years for the *San Francisco Chronicle* was a model for other journalists and news organizations to emulate.

While forging ahead with his own reporting, Shilts was sharply critical of those institutions who failed to deal with AIDS quickly and meaningfully. He targeted medicine, public health, the federal and private scientific research establishments, the mass media, and the gay community's leadership. All were part of what Randy Shilts called a "national failure, played out against a backdrop of needless death . . . (which) leaves a legacy of unnecessary suffering that will haunt the Western world for decades to come."

The indictment of the mass media is not inappropriate. While other societal institutions were clearly culpable, journalists must share the responsibility for failing to challenge the public policy makers and the experts. If a mandate of journalism is to inform and educate the public in a timely and compelling way about significant issues, then journalists truly failed to adequately inform the public about AIDS and its profound implications.

That is the ethical issue: the responsibility of journalists to hold the powerful accountable, to give voice to the voiceless, to probe the depths of the

Robert M. Steele, Ph.D., is a former journalist who now heads the ethics and press policy program at The Poynter Institute for Media Studies in St. Petersburg, Florida.

story, to pursue sources and statistics in search of the truth.

But there is more to the ethical responsibility of journalists as they cover AIDS. Journalists have a duty to care—to care about the quality of their work and about the impact and consequences it can have. And, very importantly, journalists have a duty to

It wasn't until the word epidemic was attached to AIDS that the mass media really took notice.

care about the people who are the sources and subjects of their stories.

A second significant moment in my recollections surrounding the media's role in AIDS awareness occurred in 1987 during a family vacation in Minnesota. That Sunday I picked up the *St. Paul Pioneer Press Dispatch* and spent the next hour riveted to one story. It was a story that affected me as strongly as any piece of journalism I had ever read. "AIDS in the Heartland" was written by reporter Jacqui Banaszynski. It was later to be awarded the Pulitzer Prize, the top honor in journalism.

Banaszynski's wonderfully crafted three-part series was clearly the product of months of intense observation, of vigorous interviewing and great thought. The compelling narrative was accompanied by powerful pictures from staff photographer Jean Pieri. Together Jacqui and Jean told the story of Dick Hanson, a respected farmer and political activist, and his relationship with his partner, Bert Henningson. It was a story about love, about sex, about religion and politics, about anger and frustration, about courage. It was a story about AIDS. It was ultimately a story about death.

What Jacqui Banaszynski did with "AIDS in the Heartland" was to go beyond the statistics and the policy debates. She humanized the AIDS story.

Over the course of fifteen months, this reporter came to know intimately the subjects of her story. She knew from early on that she wanted to do what she called a "diagnosis to death" story. And she knew that she would be crossing some journalistic lines that she had never crossed before, venturing into ethical issues that would challenge her very conceptions about the role of a reporter, about independence, about objectivity.

Years later Jacqui would recount a conversation she had with photographer Jean Pieri at a crucial point in reporting the story. "We're about ready to write about these guys with compassion, with sympathy, with love," Jacqui had told Pieri. "We're about ready to become involved with our subjects."

Jacqui is as good a reporter and interviewer as I have ever met. It is clear why Dick Hanson and Bert Henningson trusted her to tell their story. Yet Jacqui worried about how they would feel once the story was printed. "If I'm going to sell them a story, what if, after I sell it, they don't like what they bought? Something happens with real people when you shine the lights on them. They talk. But when the story appears in the paper it takes on a whole different cast." And, while Jacqui realized that Dick had his own motivations for doing the story—"he sees me as his vehicle for changing the world"—she also knew that she was "dealing with a man who doesn't believe he's dying."

Ms. Banaszynski felt a strong obligation to be more than honest with Dick and Bert, to lay out for them all the bad things that would happen to them after their story was published. She warned them about the hate mail and the death threats she believed they would receive and how they would regret ever doing the story. "Finally I said, 'Dick, understand I'm asking you to do the whole story, beginning to end. Dick, we both know you're going to die. I'm asking if I can watch you die.'"

Jacqui admits that there was some mutual exploitation going on. "I wanted a good story and they wanted somebody who would tell their story in the mainstream press." But she knew that her personal journalistic instincts to get the story must be balanced with responsibility and ethics. She knew that she must care about the quality of the work and the consequences it would bring.

At a crucial juncture in the reporting process, Jacqui did what many reporters never consider: "I told Dick and Bert I would tell them about what I would write." While she retained her independence over the final copy for the story, she also involved her subjects in the discussions of what the story would include. It was an important step in ethical decision making and a reflection of what I would call a "duty of care." Jacqui demonstrated a strong sense of concern and compassion for the people in her story by including them in the process. She did not fall into the trap of using her story subjects as a means to an end. She treated them with dignity, respect and fairness. Jacqui also demonstrated a strong sense of care for the authenticity and accuracy of the story by insuring that her observations and her assumptions were logical and correct.

Reporting this story created a fine line for a journalist to walk. It was made all the more difficult as Jacqui and Jean realized the personal connections that easily develop when one is immersed in the lives of those being covered. "When we came to the farm we'd get big hugs and pumpkin pie," Jacqui remembers. There was a good side to that, a solidifying of a relationship that spoke of warmth and trust. But there was also a concern, one prompted by Jacqui's continuing role as a journalist. "I'd say 'beep-beep, reporter alert,' and remind them what I was doing."

Jacqui also knew that her editors at the paper played an important role, not only on the content of her stories but on how she was doing her work. Never one to be trapped by traditional definitions

Journalists have a duty to care about the people who are the sources and subjects of their stories.

of objectivity that can lead to sterile reporting and writing, Jacqui was still aware of the importance of keeping her journalistic perspective and not becoming too emotionally involved with the people or the issue she was covering. "I'd also be very honest with my editors to the point of beating it in the ground. I'd tell them I crossed the line. They are changing my life. I'm changing their lives, I'd tell my editors. I told my editors they needed to make sure I'm not whitewashing this and making heroes out of these guys." This collaborative process between reporter and editor provided a good check and a balance, serving both journalistic ethics and journalistic excellence.

Her writing was candid, clear and compelling. It did not spare readers the agony of AIDS. She wrote of Dick's blinding headaches and failing vision, relentless nausea and deep fatigue, falling blood counts and worrisome coughs and sleepless, sweat-soaked nights.

Jacqui also wrote with poignancy and specificity of deep anger expressed by Dick's family over his lifestyle and his illness. She "sold" the family members on "telling their pain" to her, and then she watched "in the next four hours what a psychotherapist would pay big money to see."

She left that intense meeting with the family "sick to my stomach." Later she offered to call each family member independently and tell them how she quoted them and how she had described each of them in her notes. She told them "if you can convince me I've erred, I'll change it." Jacqui says nobody asked her to change anything.

In her series, Jacqui included deeply revealing elements of the family's conversations, but she also left out one particular quote from Dick's brother that spoke of his hatred for Dick and what he would like to do out of anger. It was a choice she made, a choice among competing principles. In that instance and in many others in the reporting of this story, Jacqui chose alternatives to balance her responsibility as a truth teller and her responsibility to minimize harm to vulnerable individuals.

"AIDS in the Heartland" is a model of brilliant journalism. Ms. Banaszynski's reporting and writing convey accuracy and authenticity, capturing the reality of the moments and the context of the larger issues. Her journalism is very personal in her modus operandi and in the deep portraits she paints of human beings and relationships. Her work demonstrates courage and compassion, a zeal for telling powerful stories about significant societal issues.

"AIDS in the Heartland" is a wonderful journalistic model for others to build upon. In its quality and in its approach, this reporting reflects a strong "duty of care" that is essential to the ethics of journalism. It is a duty that all news organizations and every journalist must accept, a duty to commit the resources and the expertise to coverage of what is clearly one of the most complex and important issues of our time. It is a duty to make a difference on something that matters greatly.

References

- Banaszynski, Jacqui. "AIDS in the Heartland," *St. Paul Pioneer Press Dispatch* (June 21, July 12, August 9, 1987).
- Banaszynski, Jacqui. Comments on "AIDS in the Heartland" from seminar at the Poynter Institute for Media Studies, St. Petersburg, FL (November 19, 1990).
- "Journalism's Best: The 1987 Sigma Delta Chi Distinguished Service Awards: What the Winners Did and How They Did It," *Quill* (June, 1988).
- Shilts, Randy. *And the Band Played On: Politics, People, and the AIDS Epidemic* (New York: St. Martin's Press, 1987).
- Steele, Bob. "Doing Ethics: How a Minneapolis Journalist Turned a Difficult Situation into a Human Triumph," *Quill* (November/December, 1992): 28-30.