

A Case of Need: Media Coverage of Organ Transplants

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THE CASE

The call came into Portland, Maine, newrooms on a snowy day in early February 1988.¹ Norma Lynn Peterson, a seven-year-old from the neighboring town of Windham, had end-stage liver disease. Doctors said that, without a liver transplant, Norma would be dead within a year.

She was a candidate for a liver transplant at the well-respected Pittsburgh transplant center. Until her donor organ was allocated, there was little for Norma and her family and friends to do but worry about money. Norma's illness was a financial burden for the working class Peterson family. Her father's health insurance would cover 80 percent of the \$200,000 surgery and associated medical costs, but that left at least \$40,000 that the Petersons needed to save their little girl's life. And those were just initial costs. Cyclosporine, the drug that Norma would take to stave off rejection of the transplanted organ, would run at least \$3,000 a year for the rest of her life.

That's what the phone calls to the *Portland Press-Telegram* and the ABC, NBC, and CBS affiliate stations were all about. A Valentine's Day potluck dinner had been planned in support of the Norma Lynn Fund. Ed Jandreau, the volunteer fundraiser, suggested to news directors and reporters that the community effort would make good news.

News media agreed. Stories on Norma Lynn appeared from mid-February through her triumphant return home from transplant surgery in August. Nearly all carried information on where contributions could be sent, although few let the audience know that medical insurance would cover the lion's share of the bill. In all, Norma Lynn commanded more than 200 column inches and more than two and one-half hours of airtime. "Every time something happened to Norma Lynn," said Jandreau, "the news media were there."

In the months before her transplant, Norma Lynn's need became public drama as well-wishers waited to see if a liver would be found in time. Cards, letters, and testimonies to her bravery poured in from fans across the state. Local merchants donated various items including a video camera, carloads of stuffed toys, and almost anything that would make the child happy or the waiting easier.

"Norma Lynn wanted a puppy," her mother said. "So I went to the pet store, but it was like \$425. I figured I could pay \$50 a week. So, I asked the manager and she said, 'Norma, do you want this puppy?' and she says, 'It's yours.'"

Norma Lynn's fund topped \$100,000 by the end of 1988. The little girl's classic good looks and her family's willingness to let television cameras bring their medical crisis into homes across the state paid off.

Cameras stayed close by during her surgery on May 20 and at her "press conference" at the transplant center a few weeks after her operation. News media stood watch as she recovered from two complications: a leaking bile duct and a viral infection. They documented her triumphant return home. She shared the donated private jet ride from Pittsburgh to Portland with a television reporter and videographer, whose stations had paid \$900 in jet fuel to get this exclusive coverage.

On the surface, the Norma Lynn coverage seems like a media success story. Media critics would argue that, for a change, the news underscored the positive — the community rallying around Norma Lynn — instead of the negative elements that so often command media attention. Journalists find stories like this satisfying. The family welcomes them; sources are eager to talk; there is no hidden agenda; everyone has the child's best interests at heart. But, there are difficult ethical problems just below the surface of this typical human interest story. Here I will raise some of those questions, discuss how the principals in the Norma Lynn case responded to those issues, and then provide suggestions for a style of medial coverage that would avoid the problems identified.

THE NEWSWORTHINESS OF TRANSPLANT CANDIDATES

The first obvious question is: What made Norma Lynn news? Many children and adults have life-threatening illnesses. Many are in financial need. It's unlikely that Norma Lynn was the first liver transplant recipient in the state, or the youngest.²

While journalists cited Norma's exceptional good looks as helping her get coverage, the news directors in the Portland market credited community spirit with creating the news story. Peter Wyle, news director for WMTW, the ABC affiliate, said, "It was more than the story of a little girl who needed a transplant. It was about how her neighbors and friends got a lot of support for her."

Jim Sanders, news director for WGME, a CBS affiliate, agreed. "We covered Norma Lynn so that this community would know that there was something some people in this community care enough about to give up their time, their energy to do something for this little girl. That's the story for us."

But, family and friends talk about the news coverage in a different way. "The whole thing with the media was to get some money for Norma because she's always going to need money," said Louis Peterson, Norma's father.

Her mother said that parents of other transplant candidates should get news attention as quickly as they can. "We knew a couple of families in Pittsburgh. . . . The transplant's done and they don't have the funds they need because they didn't have the media involved to help them out."

While the news directors said that they covered Norma Lynn because of the community's participation in fundraising, Jandreau, who coordinated activities for the Norma Lynn Fund, said attracting media coverage was the primary fundraising activity. Jandreau said that they planned a potluck supper at the local church on Valentine's Day for the initial event and then called newsrooms: "I said I've got a story in Windham, a human interest story. There's a little child in Windham who needs a liver transplant."

News media arrived and made the story their own. News coverage then became the primary fundraising tool. "Every time Norma Lynn's face appeared on TV," Jandreau said, "we received oodles of money more. If it weren't for the media, the Norma Lynn Peterson fund would not be where it is. We would have \$5,000-\$6,000. . . . The more coverage we got, the better off we were."

Jeff Marks, news director for television station WCSH, conceded that the news coverage certainly helped Norma Lynn, although that was not the station's intent. "As long as our driving purpose was not to raise money for Norma Lynn's surgery, and we kept the arm's length we need to keep, we cannot help that there were some good outcomes from our coverage. I would say that the people who were behind the Norma Lynn case did skillfully use the media opportunity." However, WCSH sometimes closed stories on Norma Lynn by providing the address of the fund for viewers who wished to make donations.

What made Norma Lynn news seems to be her family and friends' ability to manipulate the local news media. No one can blame the fundraiser for attempting to enlist the media's support, but one can question the media response. The news directors, in this case, claim they covered bona fide events of community interest. The fundraiser and family maintain that there were no bona fide events and little community interest until news media turned the public eye in their direction. It's disturbing to think and difficult to believe that journalists could be fooled so easily.

The television stations and newspaper published the address of the Norma Lynn Fund at the end of news stories. The journalists were blatantly participating in the fundraising effort. But, if they admitted to doing so, they would have new problems. If they are encouraging people to send money to a particular cause, don't they incur some responsibility to make sure that those funds are used appropriately? And, as a matter of fairness, shouldn't they give the same effort to others in similar situations? It's far easier to say that some people are news and some are not. The clear implication of what some called the media circus for Norma Lynn is that other needy people would not profit in the same way.

WHO GETS COVERED?

From a cynical perspective, we could say that what made Norma Lynn news is that another child's need hadn't been news the week before. One news director said, "If we tried to do every transplant, we'd be doing the transplant hour."

In every news market, there are more people in need than those who receive publicity. In Maine that summer of 1988, at least one of those was a 24-year-old wife and mother.

While Norma Lynn was recovering from surgery, Cindy Short traveled to Pittsburgh to become Maine's first heart and lung transplant recipient. Unlike the Petersons, the Shorts had no health insurance; the

cost of the surgery was picked up through Medicaid. Unlike the Petersons, the Shorts didn't know how to ask for or receive media attention. Steven Short, Cindy's husband, said that they knew about Norma Lynn from watching television and from seeing the media coverage in the hospital in Pittsburgh. "It's sad that they do so much for one and nothing for another one," Short said.

Cindy did not survive her surgery. "She died in the hospital and it was kind of rough," said Steve. "I had to find my own way back. The state won't pay for your lodging, your food down there or for flying back."

Short said that the day his wife died, he got ready to hitchhike back to his four-year-old daughter. Someone at the hospital became aware of his need and paid for an airline ticket for his return home. No news media were aware of the Shorts at the time, but it doesn't follow that they would have received coverage if their need had been known. Marks from WCSH said, "It is not the job of news media to apply attention equally to all people who may be in the same situation. Just because Norma Lynn was an interesting story doesn't mean that all transplants should be featured in news coverage."

From a media relations viewpoint, it's clear that news organizations who make decisions like this without a policy are heading for trouble. The father who calls the newsroom a week after a media blitz on one child and is told that his son's need isn't news isn't likely to understand "that's just the way news is." When editors and news directors decide who gets media attention and who does not, they are literally playing God.

Although not listed as clinical criteria, transplant surgeons will talk off-the-record about the financial requirements for transplant recipients. Potential transplant candidates will often not be put on the list to be matched with a donor organ until they show proof of insurance, Medicaid reimbursement, or a minimum of \$50,000. For some people, the kind of boost that the news media bring to fundraising can be a matter of life or death.

RESPONSIBLE COVERAGE OF ORGAN TRANSPLANTATION

No one can deny that, at least within the United States, the news media can cover whatever they choose. That is, a news organization isn't legally accountable to anyone for what they do or do not cover. But, it doesn't follow that all coverage is responsible coverage. The hallmarks of

responsible coverage can be found in understanding the social function of the press.

The news industry and individual media representatives are awarded special privileges and constitutional protection in this society. This wasn't an arbitrary gesture on the part of the framers, and it certainly isn't accidental that these privileges and protections still continue. Representatives of the news media warrant special treatment because they fulfill a particular and needed social function. It's primarily up to the news media to provide people with the information that they need to be self-governing citizens in a participatory democracy (Elliott, 1986). A responsible news organization will fulfill this duty while avoiding causing harm unless reporters and editors have adequate justification for doing otherwise (Gert, 1989). The technicalities of how this is possible is an interesting discussion but not necessary to explicate the issue at hand. The relevant question for the coverage of organ transplants is what constitutes responsible media attention to the issues and, by extension, what does not. What do people need to know about organ transplantation, so that they have the information necessary to be self-governing citizens in a participatory democracy?

Technological Advances

News coverage of experimental transplantation — xenographs, artificial organ substitutes, new and multi organ attempts — is legitimate, even though that means focusing on individual cases. These cases are unique. Interestingly enough, the potential for manipulation of news media for fundraising is not an issue here. Because of the experimental nature of the procedure, clinical costs to the patient are absorbed as research expenditures. The patient incurs the costs in a procedure which is not experimental.

The Real Costs of Extraordinary Medical Procedures

Why does transplant surgery cost hundreds of thousands of dollars? The common answer is that the talent and equipment necessary to complete the complicated procedures is very expensive. If so, then why are there so many transplant centers? Why is it necessary to fund more than one transplant center in a region when the result is competition between transplant teams for the same donors and candidates? Why does it cost so much and how is the health care dollar being allocated to meet those costs?

Access

Who are the candidates for extraordinary medical treatments such as transplantation, and who are the recipients? Beyond clinical considerations, how are determinations made about who should receive organs? Ability to pay is an important criterion, as is the perceived worthiness of the candidate. How often is a white child with medical insurance given a liver transplant; how often is a black adult alcoholic with a cirrhotic liver and no medical insurance denied?

Dilemmas

It's important for people to know that they and their families can designate that their organs and tissue be donated at death. But it's also important that the more subtle issues find their way into the public dialogue. If one's organs are one's property, as they evidently are if people can choose to donate them or not, then why can't people sell them? We allow blood products to be sold. Why not kidneys or bone marrow? On the other hand, since there are clearly not enough organs available for people who need them, why not declare citizens' organs a national resource and distribute what can be harvested from cadavers as needed?

Informed Decisions about Health Care Policy

Organ transplantation, particularly if funded through state Medicaid programs, uses a portion of the health care dollar not available for other items like prenatal health care. And, while we've decided that some services, such as police protection and public education, should be universal we have made different decisions about health care. However, since these decisions are rarely juxtaposed in news stories, it's not surprising that the public would consider individual aspects in isolation.

CONCLUSION

So what does this mean for the coverage of Norma Lynn and other individual transplant candidates? It doesn't mean that individual cases cannot be covered, but that they should be covered differently.

The larger issues listed were not addressed in the story of Norma Lynn's transplant. Marks, the news director from WCSH said, "It was easy TV journalism. It could have used some probing and depth. The

question of whether this is a good way to raise money for critical surgery is a good question. We didn't deal with that." Upon reflection, he said, "I think we should have stepped back and said, 'Why is it that they should come to the media? Why is it that they have to have bake sales?'"

Individual cases can be used to illustrate the larger issues, but the societal issues should not be lost in the drama of covering an individual case. A child in need of community assistance so that she can get life-saving medical treatment is not episodic, it is a vivid symptom of a health care system in need of attention. When news organizations cover the child in need without turning the public's attention to why the child is in such need, they become part of a system that exploits sick children to finance health care.

NOTES

1. This synopsis and all quotes are taken from the 1988-89 research and production of *A Case of Need*, a documentary film distributed by Fanlight Productions and produced by Deni Elliott and Bill Fitz in 1989.

2. It's also not known how many there have been. Each of the more than 70 liver transplantation centers in the United States keeps separate lists of candidates. Since a person can become a candidate at as many transplant centers as is financially and clinically feasible, the focus of the tracking is by procedure and center rather than by the candidate's state of origin. UNOS, the National Organ Procurement and Transplantation Network, may have this information available sometime soon. And, due to patient confidentiality, identities of transplant donors, candidates, and recipients are not released by the medical community without permission.

