

Medicine and the Movies: *Lorenzo's Oil* at Century's End

Life has meaning only in the struggle.
Triumph or defeat is in the
hands of the Gods . . .

So let us celebrate the struggle!

—Swahili Warrior Song, *Lorenzo's Oil*

With rapid developments in biomedical sciences and optical technologies, medicine and the movies came of age together in the 20th century (1). The relationship between them has intrigued a number of observers and scholars (2–4). Although the earliest movies about medicine were simple comedies about quacks, such as *Dr. Dippy's Sanitarium* (1906), serious feature films about physician-researchers and biomedical scientists began to emerge from Hollywood studios in the 1930s and helped usher in the heroic age of American medicine (5). Some of these films were biographical; others incorporated characters based, however loosely, on real scientists. Movies such as *Arrowsmith* (1931), *The Story of Louis Pasteur* (1936), *Yellow Jack* (1938), *Dr. Ehrlich's Magic Bullet* (1940), and *Madame Curie* (1943) portrayed scientists as heroes and focused on the bright promise of biomedical research to control, if not eradicate, disease through the discovery and development of vaccines and antibiotics.

In the decades since, medicine has delivered far more than its early promise—not only antibiotics and vaccines but also such seemingly miraculous advances as kidney dialysis, organ transplantation, psychotropic drugs, artificial joints, even early versions of artificial organs. Yet despite this progress, the heroic age of medicine in the movies began to fade in the 1960s. Classic films such as *M*A*S*H* (1970) and *One Flew over the Cuckoo's Nest* (1975) marked a clear break with the earlier heroic era of cinematic medicine. As physicians assumed anti-heroic status, patients themselves often became the heroes of medical movies, which depicted their struggles against death from diseases that medicine still could not treat (as, for example, in *Love Story* [1970], *Terms of Endearment* [1983], *Shadowlands* [1993], and *Philadelphia* [1993]) or, ironically, their struggles against the best efforts of doctors and medical technology to keep them alive under conditions the patients believed made life not worth living (as in *Whose Life Is It, Anyway?* [1981]).

At century's end, the relationship between medicine and the movies, like that between medicine and the lay public it serves, has become far more complex. If anything, popular movies now have greater influence on public attitudes and behavior, even on public policy, than they did earlier in the century. They can create problems for physicians in many ways—some as straightforward as misinforming patients about the efficacy of specific medications, some as subtle as undermining patients' trust in the entire enterprise of medical research. *Lorenzo's Oil* (1992) is an excellent example of a film that has both straightforward and subtle influential power. It provides a case worth examining not only for its own story but also for what it reveals about a movie's ability to work on many levels at once and thereby transcend its own particularities to illuminate wider aspects of medical and cultural realities.

A well-crafted and compelling film, *Lorenzo's Oil* is based on the true story of Augusto and Michaela Odone, whose 5-year-old son Lorenzo was diagnosed in 1984 with adrenoleukodystrophy (ALD) (Figure 1). Told there was no treatment for this progressive demyelinating disease that would probably kill their son within 24 months, the Odones began their own intensive research efforts, convened the first international scientific symposium on ALD, and developed a treatment known as “Lorenzo's oil” (the triglycerides of monounsaturated oleic acid and erucic acid, four parts to one), which reduced their son's very-long-chain fatty acids (VLCFAs) to normal levels and, they believed, reversed some of the neurological damage that he had suffered. Lorenzo, who celebrated his 22nd birthday on 29 May 2000, has now outlived his mother, who died on 10 June 2000 at the age of 61. The Odones set up a foundation known as The Myelin Project to fund research that they hoped would someday lead to successful remyelination of Lorenzo's nerves and restoration of normal brain function for him. They coauthored biomedical articles, letters, and chapters that were published in prestigious biomedical journals and books (6–8), and Augusto Odone was awarded an honorary doctorate from the University of Stirling in Scotland (9). Even in this schematic, summary form, theirs is an amazing story, one guaranteed to catch the attention not only of other parents of boys with ALD but also of patients with other terminal illnesses for which there is currently no treatment.

Figure 1. Susan Sarandon, Nick Nolte, and Zack O'Malley Greenburg (as Michaela, Augusto, and Lorenzo Odone) in *Lorenzo's Oil*.



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Lorenzo's Oil received generally favorable reviews in the lay press (10–12) and garnered Golden Globe and Oscar nominations for Susan Sarandon for best actress and an Oscar nomination for cowriters George Miller and Nick Enright for best original screenplay. Miller, an Australian physician, is also the director and coproducer of the film (13). The remarkable clarity with which the film explains the genetic and biochemical background of Lorenzo's malady and the Odone's search for a treatment is usually attributed to Miller's medical training. Lay critics praised the film for its compelling story, excellent acting, and skilled cinematography. Their most frequent criticism—Nick Nolte's phony-sounding Italian accent—was relatively minor.

Reviews of the film in medical journals were far less favorable (9, 14–16), focusing on the factual inaccuracies. Dr. Hugh W. Moser, the ALD expert on whom the film's character Dr. Gus Nikolai (played by Peter Ustinov) is based, summed up his objections by saying, "As a work of fiction, *Lorenzo's Oil* is an excellent film. However, as a factual documentary it has three main flaws: it overstates the success that can be achieved with the oil, it invents conflicts between the parents and the medical establishment, and it presents an inaccurate and malicious portrayal of a valued parents' organisation [the United Leukodystrophy Foundation]" (14). Moser also objected to the film's depiction of Lorenzo's enrollment in a trial that restricted dietary VLCFAs, because that trial had ended in 1982, before Lorenzo became his patient (14, 16). When asked about such inaccuracies, Michaela Odone replied that she "never threw her sister out of the house or slapped her husband" as she is portrayed as doing in the film and that she "can't answer for Hollywood and its use of symbolic representations rather than documentary accuracy" (17).

Although the film did not proclaim itself "a factual documentary," it was presented (and generally accepted) as a true story. Publicity surrounding the 14 December 1992 world premiere of *Lorenzo's Oil* in Washington, D.C., which was a benefit screening for The Myelin Project, as well as the flyers that were distributed in theaters showing the film, reinforced the film's real-life truth (18). Viewers who missed the film's first run and who watch it now on home video are welcomed by Nolte and Sarandon, who introduce the film by saying: "Our new film, *Lorenzo's Oil*, chronicles Augusto and Michaela Odone's courageous struggle to save their son's life. And now the Odone's are writing the second chapter in the miraculous story. It's called The Myelin Project, and it's providing real hope to thousands suffering from diseases such as multiple sclerosis." The introductory blurb ends with Sarandon giving the toll-free telephone number of The Myelin Project and urging viewers to call and pledge their support. Thus, viewers are primed to see the film as a true chronicle and to interpret it as a "courageous struggle" and a "miraculous story." Few who see the film are likely to notice the statement that comes in small print at the end of the film, after a very long list of credits and the copyright notice: "This is a true story although certain characters and incidents are fictional." Even those attentive few who do see the notice have no way of knowing which are the fictional characters and incidents.

Part of the film's power and persuasive influence surely comes from its perceived truth, and physicians prominent in ALD research understandably want to set the record straight (14, 16, 17, 19). But the film's greatest power comes from the skillful way in which the writers and cinematographer have limned the Odone's story over ancient mythic patterns that still resonate in our culture. The filmmakers use Christian iconography, holidays, and ceremonies to mark the progression of Lorenzo's illness, and they juxtapose scenes in a way that identifies Lorenzo with the crucified Christ, who suffered so that others could be saved. Against the grain of this Christian imagery, however, run basic elements of ancient Greek tragedy: the Odone's use their superior intelligence and perseverance to struggle against their son's fate. These mythic patterns in the film create a richer, far more complex text than a medical or journalistic account of Lorenzo's case would give. Viewers are moved as much by the Odone's dramatic struggle as by the disputed facts of the case.

Lorenzo's Oil opens in the beautiful Comoro Islands, off the East African coast, in July 1983. For the Odone's, this is the Garden before the Fall: Lorenzo is a beautiful, vibrant, active young boy. After the family's return to Washington, D.C., in the fall of 1983, Lorenzo begins to have uncontrollable destructive outbursts, first at school and then at home. On Christmas Day 1983, he falls—first off his new bike; later, after a trip to the emergency room for sutures, from a chair beside the Christmas tree, which falls beside him. But it is not until Easter weekend, April 1984, that Lorenzo is hospitalized for tests that will lead to a conclusive diagnosis. The juxtaposition of scenes of Lorenzo patiently enduring several high-tech medical tests with scenes of midnight mass links Lorenzo's suffering with Christ's. This identification is further emphasized by a scene in the cathedral in which the covering is removed from a statue of the Virgin Mary holding the Christ child, who is about Lorenzo's size. Later in the film, Michaela is shown holding Lorenzo in a similar pose—that of the pietà.

Even while these scenes reinforce Lorenzo's identity as a substitute Christ, other scenes in the cathedral sequence prepare for the substitution that soon comes of scientific research for religious faith (20). Many of the scenes of Easter mass are shot from high above, focusing first on the priest and his acolytes; then, moving in closer, on the heads of Michaela and Augusto Odone, bowed in prayer; finally, moving in closer still, on Michaela's tearful face raised hopefully, as background music soars. Later in the film,

Figure 2. Despite their lack of medical and scientific knowledge, Augusto and Michaela Odone (portrayed by Nick Nolte and Susan Sarandon) resolve to learn all they can about their son's illness.



Lorenzo's Oil. Copyright 1992 by Universal City Studios, Inc. Photograph by Mikki Ansin.

similar high-overhead shots are used to show Michaela and Augusto, never again at mass but often, in turn, as they are doing research in the library of the National Institutes of Health in Bethesda, a secular cathedral to science (Figure 2). The supplanting of religious worship by scientific research is made more explicit by other aspects of the film. For example, after Michaela learns that she is the carrier of the X-linked genetic defect that has caused Lorenzo's illness, her sister makes it clear that Michaela, who has stopped going to church, feels "singled out by God for special punishment" and devotes herself to the fierce and unrelenting drive to save her son's life in an effort to expiate her guilt for causing his suffering. When Augusto proposes that they undertake the same kind of intense study for understanding and dealing with Lorenzo's illness as they undertook in preparation for their years in the Comoros, Michaela is ready. They then begin their desperate self-education in genetics and biochemistry, which leads to their conceptual understanding of the fatty-acid manipulation that may bring Lorenzo's VLCFAs to normal levels, if only they can find someone to undertake the difficult fractionation of erucic acid. Their perseverance eventually leads them to Don Suddaby (who plays himself in the film), a biochemist at Croda Universal in Hull, England, who succeeds in producing the form of the oil that the Odone's need for their experimental treatment for Lorenzo.

In the film, the saddest aspect of the Odone's story is

that they struggle so heroically and successfully to find a way to bring Lorenzo's VLCFAs back to a normal level, yet the treatment comes too late to save Lorenzo from the devastating effects of ALD; the severe neural damage that he has already suffered cannot be reversed unless his nerve cells can be remyelinated. Admiration for the Odone's increases as viewers see them take comfort in the prospect that, as a result of Lorenzo's suffering, other boys who have ALD will be saved because they will be able to take Lorenzo's oil to stop the disease from progressing. The film closes with beautiful images of frescoes of angels, followed by cameo shots of several healthy looking boys who say that they have ALD but have been taking Lorenzo's oil and are doing fine.

In the years since the film's initial release, the deeply tragic nature of the Odone's heroic struggle has continued to unfold as several controlled clinical trials have shown that elevated VLCFAs may be the biochemical marker of ALD but are not the cause of the disease—at least, not the only cause. Even in patients whose VLCFAs have been normalized with Lorenzo's oil, ALD can progress (21–24). Within the limits of human knowledge in the 1980s, the Odone's did the best anyone could possibly have done to find the treatment they expected to cure ALD. But the outcome, as Greek and Swahili legends caution, was—as always—in the hands of the gods. That this is so heightens rather than diminishes the magnificence of the Odone's struggle. In celebrating their struggle, the film achieves its greatest power.

The legacy of the film, which has been extended indefinitely by its availability on video, presents two major problems for physicians. The first is straightforward; the second is not. First, physicians must correct the false hopes raised by the film's overly optimistic claims regarding the efficacy of Lorenzo's oil. Second, they must acknowledge that there is an inherent conflict between the goals of physician-researchers and those of terminally ill patients and their families. This conflict is unlikely ever to be resolved, and it cannot be argued away, no matter how much evidence researchers try to provide to the contrary (14, 16). The Odone's understood this very well. In an interview about the film, Michaela Odone said, "Our message to parents is: realize that your interests and the doctors' interests are not parallel. You may have a motivation and a time limit that these people do not have" (19). In 1997, Augusto Odone observed succinctly that "researchers and the families of afflicted people have interests and sensitivities

that do not always coincide" (25). If physicians limit their response to *Lorenzo's Oil* to correcting its scientific details, they may miss this larger message of the film, which transcends the Odone's personal story. The inherent conflict between researchers and the patients who need their help (26) is also dramatized in the 1999 Pulitzer prize-winning play *W;t* (27), and the subject has received much attention in the news since the death of Jesse Gelsinger in 1999 from adverse side effects experienced during a gene-therapy trial at the University of Pennsylvania (28).

At century's end, the relationship between increasingly knowledgeable and sophisticated U.S. patients and their doctors—clinicians or researchers—is more complex than ever (29). Among movies from the last decade of the 20th century that have focused on physician-researchers—such as *Awakenings* (1990), *Medicine Man* (1992), and *Outbreak* (1995)—*Lorenzo's Oil* stands out because it helps us reflect on the complicated nature of that relationship and because it reminds us of the importance of mythic and symbolic ways of understanding human experience. The reflection and the interpretive skill that a film such as *Lorenzo's Oil* fosters in its viewers can stand physicians in good stead as they engage in their multilayered interactions with patients and families.

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Acknowledgments: The author thanks Donna A. Vickers for her research assistance and Robert L. Jones and an anonymous reviewer for their helpful comments on a previous version of this essay.

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Ann Intern Med. 2000;133:567-571.

References

1. Crawford TH. Visual knowledge in medicine and popular film. *Lit Med.* 1998;17:24-44.
2. Dans PE. *Doctors in the Movies: Boil the Water and Just Say Aah.* Bloomington, IL: Medi-Ed Pr; 2000.
3. Banks JT, ed. *Moving pictures.* *Lit Med.* 1998;17:1-176.
4. Gabbard GO, Gabbard K. *Psychiatry and the Cinema.* 2d ed. Washington, DC: American Psychiatric Pr; 1999.
5. Jones AH. *Medicine and the physician.* In: Inge MT, ed. *Handbook of American Popular Culture.* 2nd ed. New York: Greenwood Pr; 1989:721-43.
6. Rizzo WB, Leshner RT, Odone A, Dammann AL, Craft DA, Jensen ME, et

- al. Dietary erucic acid therapy for X-linked adrenoleukodystrophy. *Neurology*. 1989;39:1415-22.
7. **Odone A, Odone M.** More on Lorenzo's oil [Letter]. *N Engl J Med*. 1994;330:1904-5.
8. **Rizzo WB, Leshner RT, Odone A, Craft DA, Jennings SS, Jaitly R, et al.** X-linked adrenoleukodystrophy: biochemical and clinical efficacy of dietary erucic acid therapy. In: Uziel G, Wanders RJA, Cappa M, eds. *Adrenoleukodystrophy and Other Peroxisomal Disorders: Clinical, Biochemical, Genetic, and Therapeutic Aspects: Proceedings of the International Workshop on Adrenoleukodystrophy and Peroxisomal Disorders*, 10–11 November 1989, Rome. Amsterdam: Excerpta Medica; 1990:149-62.
9. **Nowak R.** "Lorenzo's Oil": Uplifting, but misleading. *J NIH Res*. 1993;5:34-36.
10. **Ebert R.** *Lorenzo's Oil*. *Chicago Sun-Times*. 1993;15 Jan. www.suntimes.com/ebert/ebert_reviews/1993/01/800178.html. Accessed 16 August 2000.
11. **Kempley R.** 'Lorenzo's Oil.' *Washington Post*. 1993;15 Jan:B1.
12. **Turan K.** A bracing prescription: 'Lorenzo's Oil' takes an unsentimental look at a boy's devastating disease . . . and his parents' struggle to cope. *Los Angeles Times*. 1992;30 Dec:F1.
13. **Dutka E.** The spark that gives 'Oil' its heat: Director George Miller follows his passion and gambles on a long-shot—a medical mystery story. *Los Angeles Times*. 1992;30 Dec:F1.
14. **Moser HW.** *Lorenzo's Oil*. *Lancet*. 1993;341:544.
15. **Rosen FS.** Pernicious treatment. *Nature*. 1993;361:695.
16. **Moser HW.** Suspended judgment. Reactions to the motion picture "Lorenzo's Oil." *Control Clin Trials*. 1994;15:161-4.
17. **Marbella J.** Troubled waters for 'Lorenzo's Oil.' *Baltimore Sun*. 1993;26 Jan:D1, 3.
18. **Odone A.** The Myelin Project: progress report. 1992;28 Nov. www.myelin.org/112892pr.html. Accessed 16 August 2000.
19. **Kolata G.** Lorenzo's Oil: A movie outruns science. *New York Times*. 1993;9 Feb:C1, 6.
20. **Pollack R.** *Signs of Life: The Language and Meanings of DNA*. Boston: Houghton Mifflin; 1994.
21. **Moser HW.** Lorenzo oil therapy for adrenoleukodystrophy: a prematurely amplified hope [Editorial]. *Ann Neurol*. 1993;34:121-2.
22. **Rizzo WB.** Lorenzo's oil—hope and disappointment [Editorial]. *N Engl J Med*. 1993;329:801-2.
23. **van Geel BM, Assies J, Haverkort EB, Koelman JH, Verbeeten B Jr, Wanders RJ, et al.** Progression of abnormalities in adrenomyeloneuropathy and neurologically asymptomatic X-linked adrenoleukodystrophy despite treatment with "Lorenzo's oil." *J Neurol Neurosurg Psychiatry*. 1999;67:290-9.
24. **Moser HW.** Treatment of X-linked adrenoleukodystrophy with Lorenzo's oil [Editorial]. *J Neurol Neurosurg Psychiatry*. 1999;67:279-80.
25. **Odone A.** The Myelin Project: progress report. 1997;29 May. www.myelin.org/052997pr.html. Accessed 16 August 2000.
26. **Pollack R.** Introduction. In: *The Missing Moment: How the Unconscious Shapes Modern Science*. Boston: Houghton Mifflin; 1999:1-11.
27. **Edson M.** *W;t*. New York: Faber and Faber; 1999.
28. **Stolberg SG.** Youth's death shakes new field of gene experiments on humans. *New York Times*. 2000;27 Jan. www.nytimes.com/library/national/science/012700sci-gene-therapy.html. Accessed 16 August 2000.
29. **Kolata G.** Web research transforms visit to the doctor. *New York Times*. 2000;6 Mar. www.nytimes.com/library/tech/00/03/biztech/articles/06inte.html. Accessed 16 August 2000.