

The greatest attraction of this report is its lucidity. The conclusions are predictable, if a trifle disappointing. Despite the handicaps of the study, the authors identified the following as measures to be taken for protection of participants' rights:

- Setting up a worldwide, compulsory trial register in which all involved parties including the contractors and subcontractors are disclosed.
- Increasing the number of regulatory inspections of trial sites in non-traditional trial regions.
- Including in Marketing Authorisation Application procedures independent verifications that the drugs have been tested in accordance with the Declaration of Helsinki.

- Involving independent organisations that promote the interest of clinical trial participants in audits of trial sites conducted by sponsors and CROs.
- Involving clinical trial participants in inspections and audits, so that their perspective on the ethical conduct of the trial is included.
- Making audit and inspection results publicly available.

That would be a good way to go.

Reference

1. Mohan A. Ethics and contemporary urology practice: setting out principles. *Indian J Urol* 2009;25:340-2.

Human building blocks of research

PR KRISHNASWAMY

Adjunct Professor of Biomedical Research, Sri Devaraj Urs Academy of Higher Education and Research, Sri Devaraj Urs Medical College, Kolar 563 101 Karnataka INDIA e-mail: p.r.krishnaswamy@gmail.com,

Rebecca Skloot. *The immortal life of Henrietta Lacks*. Macmillan Publishers Ltd; 2010. pp. 368 £18.99

The immortal life of Henrietta Lacks is non-fiction of a rare quality in creative writing. The author, a science journalist, weaves a multilayered narration about medicine, medical research, faith, racism, poverty, and ethics with a skill that renders to her composition an "immortal quality".

Henrietta Lacks was an African-American woman, a mother of five children, who died of cervical cancer in 1951, at the age of 31. At the Johns Hopkins Hospital in Baltimore, United States, where she was receiving treatment, tissue specimens were taken from her cervix for research, without her knowledge. The specimens turned out to be the source of the first viable and amazingly productive cell line - the famous HeLa cells so familiar to all engaged in medical and cell biological research. The cells became the fountainhead of a range of medical discoveries, research applications, therapeutics and vaccines. The book provides a human face to the many ethical issues concerning the HeLa cell line.

The cervical tissue specimen was used by George Gey at Johns Hopkins. Gey's assistant labeled the tubes where the cells were stored "HeLa". The cells doubled in number every 24 hours and never stopped. Since then many trillions of cells have been produced and used in laboratories and factories all across the globe and are robust even after 60 years. The polio vaccine, the drug tamoxifen, gene mapping, in vitro fertilisation, treatments for influenza, leukaemia, Parkinson's Disease are all applications which have harnessed the biological potential of HeLa.

Science is not the only fascinating aspect of this book that lifts it to the rank of a best seller; nor is it the central theme. The

author, in her exploration along with Deborah, the daughter of Henrietta, who did not know her mother, has been able to knit together a story of the sad life of Henrietta, the racist norms of that period, the deprivations of African-Americans, and the almost non-existent research ethics of the mid 20th century. It is shocking that even after 20 years after HeLa became a famous biomedical research tool, Henrietta's family was unaware of these developments. Needless to say, they did not receive even a few pennies of the profits from the multimillion dollar industry in biological and cell culture based on her cells. Much later, they were even subjected to investigations without their informed consent.

In February 2010, Rebecca Skloot spoke at the Kimmel Cancer Centre in Philadelphia to a crowd of physicians and scientists, most of whom knew HeLa cells, but nothing else of their origin or history. She told the story of the young black woman who reported to the clinic at Johns Hopkins for treatment for a tumour in her cervix. She received the treatment of the time, a course in radiation. The diagnostic sample took a course of its own. It went to a cell biologist who knew nothing about its origin until it started producing manically upon culture. Mass production ensued. HeLa was distributed around the world. Skloot described the family's anguish at the fact that a vial of HeLa cells costs \$250 and some HeLa-derived products for treatment cost up to \$10,000, while many members of the Lacks family go without health insurance and treatment for their illnesses.

As research and discovery activities go global, there may be some warnings for us in India. Human subjects who participate in experiments give "informed consent". How informed is this consent? Does the consent form list all possible uses to which a specimen may be put? For example, DNA material is collected

from human subjects. Its use must be regulated and cannot be left to the goodwill and largesse of corporations which are driven by profits. What about pharmacogenetic information based on DNA collected from subjects in trials? This is of value to pharmaceutical companies.

A myriad possibilities exist and we can only address the issues by building trust and sharing among scientists, society and

industry. And we will have to travel some distance to reach that state of affairs. Unlike in the USA during Henrietta Lacks' period, we have no racial divide in India, but this is offset by economic and educational deprivation.

The book is a 'must read' for physicians, researchers, corporates in healthcare, social activists, and those engaged in medical ethics.

Talking reflections

ANOOPKUMAR THEKKUVEETIL

Head, Division of Molecular Medicine, Sree Chitra Tirunal Institute for Medical Sciences and Technology, Trivandrum, Kerala, INDIA 695 011 e-mail: anoop@scimst.ac.in

***Peepli [live]*. Aamir Khan Productions, 2010. Directors: Anusha Rizvi, Mahmood Farooqui. Hindi. 95 minutes.**

When Anusha Rizvi, a journalist who had no previous experience of movie making, came out with a movie on farmer suicides in Indian villages, the first reaction among many was surprise. It is not the sort of story one usually takes up for a career change. Neither is it part of the mainstream approach to Indian film making these days. In earlier times, meaningful stories were discussed by serious moviemakers like Shyam Benegal, Ketan Mehta, Goutam Ghosh, and others. As the intellectual middle class in our country has become more affluent, storytelling has moved from social issues to interpersonal conflicts. Still, with the change in focus we have had movies like *Firaaque* (by Nandita Das) with a serious discussion on social injustice.

Cinema has the power to remind us of the plain absurdity of our lives, and stimulate debate on how to deal with social issues. Anusha Rizvi's decision to present the subject as a satire and to underscore the callousness and hypocrisy of the media and political class in handling the plight of the poor in the country has worked perfectly. One reason for Rizvi's taking up such an approach could be because she herself knows the murkier side of Indian journalism. The race of journalists to get exclusive news for their channels and to accelerate their ratings is never ending. I remember BBC journalist Nik Gowing talking about the absurdity of television journalism, and the dangers of breaking news often without verifying facts. Satire is indeed the best way to bring out that dark side of journalism.

The movie *Peepli [live]* tells the story of two farmers, Natha and Budhia, living in a remote village, who are about to lose their land because of an unpaid bank loan. An easy solution to the problem was to avail of the government aid for families of farmers who have committed suicide because they are unable to pay off their debts. One English television channel picks up the story and, as expected, it becomes a national debate. Natha becomes a national symbol and every television channel anchor poses the question, will Natha actually commit suicide or not? Declaration of by-elections in that village also gives an extra insight on how

our government machinery works. Gradually, Natha, Budhia and family become just a backdrop and the whole scene is taken over by television journalists and politicians. Television anchors discussing farmers' suicides with politicians become the 'daily show' with 'breaking news' focusing on Natha's suicide threat. At once, we comprehend the striking similarity with our day-to-day prime time television viewing.

The advantage of satire is that one can extend the story to any level possible. Woody Allen uses satire to expose issues dealing with morality in man-woman relationships by creating characters that talk about whatever enters their minds. Chaplin used satire in his classic movie *Modern Times* to depict the plight of the working class in an industrialised society more vividly than any documentary film could have done. Here, in *Peepli [live]*, Rizvi has also tried to take it to the extreme. Besides all the laughs, the director is able to make the viewer think about the pathetic situation in which our country is. The brilliance of storytelling is in its details - like bringing in the deep-well pump into the house as one of the characters; the dream sequences of Natha; and the scene where all the characters are running around in circles trying to find Natha. The movie works by maintaining a hectic pace.

Besides, the music is a logical extension of the theme in the movie. The song *Des mera rangrez hai babu* almost summarises what present-day India is. ("*Arre India sir, ye cheez dhurandhar, Rang rangeela parjatantar*" Sir, this India is a great thing / This is a colourful democracy) A colourful democracy indeed! When the people are satisfied with the conclusion of the story (Natha's presumed death), all is quiet. The festival is over and everybody leaves the ground, except the people who live there. The character in the movie, digging the land as if to bury his own body, is a reminder that Natha's story never ends, because his life in the city could be another disaster in the making. Until he takes an unusual decision we never actually see people like him or worry about how they live. *Peepli [Live]* stands up as excellent art apart from being a mirror for our social conscience.