Imagine you are an Orthodox Ashkenazi Jew with a family history of Tay-Sachs disease (an untreatable recessive genetic disease that results in death during infancy). Your prospective marriage partner has a similar history. You each test positive as carriers of the disease. Your rabbi informs you that abortion is not an option. You and your prospective partner agree not to get married to avoid the possibility of bringing a Tay-Sachs–afflicted child into the world. Your community applauds your decision and works to find you other acceptable partners. Now imagine that you are a medical insur-er. A recently married couple, each with a family history of Tay-Sachs, applies for medical insurance. Your company insists that the couple be tested for carrier status before issuing an insurance policy. The results are positive for both applicants. Your company decides to issue an insurance policy only on condition that any pregnancy resulting in a Tay-Sachs infant will not be covered, nor will any medical costs incurred by such an infant. The insurance applicants charge that your company is coercing them to have an abortion in the case of a Tay-Sachs pregnancy.

What are the medical, social, religious, ethical, economic, and legal differences between these cases? DNA: Promise and Peril, by geneticists Linda and Edward McCabe, poses dozens of such questions. Given the importance of such questions, I wish I could recommend this book, but I cannot.

The simplistic thesis of the book is that biomedical researchers, physicians, and the public all believe that genes are destiny. The McCabes were early participants in the Human Genome Project, which has mapped all of the genes on human chromosomes. They write about their unrealistic expectations that having access to this genetic information would create a revolution in medicine, permitting humans’ entire health history to be mapped out through genetic predestination. They have become disillusioned. Genetic tests, they are surprised to discover, provide only incomplete, probabilistic information. Because environment plays a role in the expression of genes, genetic determinism may be a false and dangerous concept.

Their thesis that genes are not destiny is repeated in every chapter of the book, which includes discussions of race, sex, forensics, culture, discrimination, patents, and insurance. Having taught a course on precisely this material for nearly 15 years, I am perhaps overly aware that every chapter is flawed by odd oversights, lapses, and misrepresentations. For instance, the McCabes often give public opinion more weight than scientific evidence. While the public’s understandings and misunderstandings of genetics are essential to any discussion of how to implement genetic medicine effectively, one cannot make a case against genetic medicine based on public confusion. Lay misunderstandings indicate that better science education and popularization are needed. Two topics the authors never discuss. Also missing from the book is any discussion of the single most important group of people who interface between the medical community and the public: genetic counselors. This is an unfortunate oversight because many of the problems of misuse and abuse of genetic tests cited in the book could be addressed if genetic counseling were mandated for every individual considering or getting genetic testing.

The authors use the indeterminism of many genetic tests to rail against all forms of genetic discrimination. Unfortunately, they lump together “discriminating between” individuals, which is done with all types of medical testing as an essential part of diagnosis, and “discriminating against” individuals, which involves the misuse of tests or traits that are irrelevant to health or performance. To confuse the 2 is a disservice.

The authors misrepresent the purpose of medical insurance, conflating it with universal health care. They perpetuate the myth that insurers are eager to acquire genetic test results, ignoring the fact that having a family history often provides insurers the probabilistic data they need. They ferret out nasty cases in which employers and insurers have improperly used genetic tests to void contracts but never mention that a negative genetic test result might permit an individual to become insurable.

The McCabes disparage those who patent genes and develop genetic tests, believing such tests should altruistically benefit everyone. This seems at odds with the authors’ thesis that genes are not destiny. It also ignores fundamental economic reality. The McCabes never explain to the reader that the developmental costs of genetic tests and therapies are in the hundreds of millions of dollars. The high costs of the tests reflect the need to recoup this huge investment in making sure tests and therapies are accurate, efficacious, and safe. Patents are the only assurance a company has that it can recoup this investment. The irony is that Edward McCabe, through the University of California, Los Angeles, has genetic technology patents. Was he compelled by the institution to apply for patents he does not believe to be ethical? If so, full disclosure and a frank discussion would have been a refreshing and valuable addition to the book.

The real problem is that the McCabes raise issues without providing guidelines for resolving them. They seem to applaud the Jewish community for supporting the couple who separates to avoid having a Tay-Sachs child, but condemn the insurers who want to achieve the same end. Because there is no clear set of ethical or other principles guiding their discussion, similar conundrums constantly crop up. For example, the authors argue that there is no genetic basis for the concept of “race.” Then, in another chapter, they present a riveting case of Navajo tribal leaders refusing to give permission for investigators to use genetic samples from members of the tribe. Elsewhere, they approve the decision of the Icelandic government to make available the medical records and genetic samples of the Icelandic people to a private company. They do not discuss why...
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it makes sense for the Navajo to refuse to cooperate with developing genetic tests but it does for the Icelanders. There is no discussion about why select ethnic or political concepts are valid. Nor is there any discussion of who “owns” genetic information. Why should any group—religious, ethnic, political, or racial—be able to trump the individual in controlling access to genetic information?

All in all, this is a confusing book that could have provided a real service to practitioners and the public alike, but instead purveys misinformation.

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Financial Disclosures: Dr Root-Bernstein reports that he has 1 issued patent and a dozen pending patent applications for vaccines and adrenergic and histaminergic drugs. Michigan State University is the assignee for all of his patents. He also reports that he serves as a consultant for SRI International and that he consulted for Mitokor, Chiron, and Parke-Davis for drug development.

DEATH AT INTERVALS
By José Saramago (translated by Costa)
196 pp, $12.99

WHAT IF PEOPLE SUDDENLY STOPPED DYING?

Would it be the ultimate goal of medical science—the greatest miracle of all time, or at least a cause for widespread jubilation? Maybe not. In the lengthy fable Death at Intervals by José Saramago (the 1998 winner of the Nobel Prize for Literature), the termination of death raises plenty of questions and spawns a slew of serious problems.

In an unnamed nation of 10 million people, death disappears on January 1. The newspaper headline proclaims: “New Year, New Life.” While plants and other animals continue the normal cycle of life and death, all human beings in a single country no longer die. The euphoria associated with the thought of everlasting life on earth is soon replaced by apprehension and panic. The reality of arrested death turns out to be less enchanting than the idea of immortality. A large number of individuals already on the brink of death—the very elderly and irreversibly ill—are trapped in a state of suspended life.

The elimination of death hits some groups harder than others. Physicians and priests find themselves equally helpless. Insurance agents and undertakers struggle with the loss of business. Hospitals and nursing homes are overloaded with patients eternally poised on the edge of death. Government officials are befuddled. They decide that the absence of death is actually a bad thing. A nation without death apparently has no future. Society must deal with an entirely new set of predicaments related to the inescapable truth that elderly and chronically sick citizens are unable to pass on.

The demise of death creates a few opportunities for some. For a fee, the local crime organization offers a type of euthanasia service. They will transport individuals in a state of arrested death across the border to 1 of 3 neighboring countries where people continue to die normally. Families that cannot afford the illegal transportation of their loved ones are left with only 2 choices: cart their relatives across the geographic boundary between life and death without much assistance or care for them at home, possibly forever. Meanwhile, philosophers and religious delegates endlessly debate the significance of life without death.

Seven months later, death makes a comeback, returning as abruptly as its earlier disappearance. The grim reaper sends a letter to explain that the stoppage of death was an experiment designed “to give those human beings who so loathe me just a taste of what it would mean to live forever.” In hindsight, the interruption of death was a “deplorable” mistake. A lesson has been learned. Now, people will be forewarned of their impending demise. One week prior to their death, individuals will receive a violet-colored envelope. The gist of the message: Get your affairs in order—stat! One week later, 62 580 people die in an instant. The personification of death (lowercase d) is peculiar: a sad woman who has never slept. In her corporeal form, she looks about 36 years old and is gorgeous. As expected, she has a scythe but not much use for it until recently.

When 1 violet-colored envelope is astoundingly returned 3 times to the sender, death makes a house call to see the intended recipient. He is a 50-year-old cello player who lives with his dog. Death becomes obsessed with the cellist and his failure to die as scheduled. She talks with him and experiences human emotions. She begins to understand the essence of humanity. Next to him in bed, death holds the musician in her arms and experiences sleep for the first time. Even death is no match for love. The final image is creepy and unexpectedly tender. The novel ends exactly as it begins: “The following day, no one died.”

Transience and transformation are 2 fundamental concepts in a novel that offers many lessons about the power of love, human dignity, and truth. Hope and fear exist in homeostasis. The novel takes a few snipes at organized religion and its ability to neutralize curiosity. Fans of dark humor and irony will find plenty of both in this book.

The author’s writing style is daunting and at times wearisome. He writes sentences as long as 110 words and single paragraphs that span more than 2 pages. His failure to use quotation marks to signal dialogue is confounding. He shows disdain for capitalization. Yet his words still find their way to wisdom. Death at Intervals is not quite on par with Saramago’s masterpiece, Blindness, but it is a strangely beautiful work that is dangerous and thought provoking.

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