"A fool can throw a stone in a pond that 100 wise men cannot get out.” – Saul Bellow

Introduction

Myths and controversies have defined, and always will define, human views about the cause-effect relationship of diseases. There will always be a gap between our need to rationalize the occurrence of illness and the ability of science to provide solid, unshakable insights into its mechanism and etiologies. Throughout human history, the creation, diffusion, and impact of myths about the cause-effect relationship of diseases have been shaped by political, religious, social, psychological, and economic factors. True but misinterpreted scientific observations and charismatic scientists, whether misguided or charlatan, have all contributed to the creation of myths. For many human biological processes, the cutting-edge science of yesterday has become the irrational and ridiculous myths of today. This relentless process by which science progresses and corrects itself dispels old myths and creates new ones.

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Despite significant progress in the study of the epidemiology and genetics of autism, the etiology and pathophysiology of this condition is far from being elucidated and no curative treatment currently exists. Although solid scientific research continues, in an attempt to find explanations and solutions, a number of nonscientific and pure myths about autism have emerged. Myths that vaccines or mercury are associated with autism have been amplified by misguided scientists; frustrated, but effective parent groups; and politicians. Preventing the protection provided by vaccination or administration of mercury-chelating agents may cause real damage to autistic individuals and to innocent bystanders who as a result may be exposed to resurgent diseases that had already been “extinguished.” That such myths flourish is a consequence of the authority of scientific evidence obtained by scientific methodology losing ground to alternative truths and alternative science. This article presents a narrative of the origin of the myths around autism.
However, some myths persist long after solid scientific evidence has provided alternative explanations. Nowhere is this truer than in the field of mental and neurological illnesses, where the understanding of disease etiologies lags behind the rest of medical disciplines, and autism is no exception. The first explanation of autism was offered in the 1950s by Leo Kanner and, to a larger extent, Bruno Bettelheim, both US-based psychoanalytically oriented academic physicians. A cold, distant, and career-oriented mother, known as the refrigerator mother, was the prevailing explanation as to why some children develop severe emotional and behavioral problems. This hypothesis could not be dislodged by its lack of epidemiological evidence, biological plausibility, or by the advent of the feminist movement, or even by its ridiculous and offensive nature. Not until the 1970s and 1980s, when the psychoanalytic explanations for normal and abnormal behaviors were losing ground to biological explanations, albeit simplistic and in most cases wrong, was the refrigerator mother theory for autism abandoned.

Autism is a childhood-onset, developmental condition that in most sufferers is associated with poor communication, abnormal behavior, and life-long dependency. For centuries, manifestations of childhood autism were stigmatized as mental retardation, schizophrenia, and at best as bizarre behaviors. It was only with the publication of the third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III), in the early 1980s, that infantile autism was defined as a developmental psychiatric/neurological disorder and became the focus of basic research and clinical, educational, and social care. This change in the societal approach to autism was at least partially due to the actions of militant and vociferous parent groups. Not surprisingly, parents of affected children tend to feel respondent, angry, and guilty, searching for answers to the question, “why has this happened to my child, and to me?” For many parents, militancy in search of answers and solutions becomes a central life goal. Self-blame, such as for risk factors like careless behavior during pregnancy, a bad gene, or advanced age at conception, is often experienced by parents searching to explain their plight. However, an explanation that places blame on an external factor appears to be a more comforting one. Vaccines and, by implication, the pharmaceutical industry that stands to profit from them, as well as their co-conspirators, the scientific community and the governments supporting the vaccinations, were the perfect target for their anger and frustration.

In many regards, vaccines—and in particular, those for mumps, measles, and rubella (MMR)—have the makings of a cause-effect myth. The notion that “if B follows A, then A is probably the cause of B” is the most common misinterpretation of causality. The MMR vaccine is administered to 12- to 18-month-old children. At this age, the first signs of an impending developmental condition, such as autism, start creeping in and become noticeable. The idea that “vaccine precedes event, hence vaccine causes disease” fits the cognitive bias to search for patterns and is much more comforting than the notion of coincidence or bad luck. A simplistic explanation, such as the claim that the emerging but still weak immune system of the toddler is overstimulated and damaged by the vaccine, adds credibility to the cause-effect sequence. At the same time, the current and future benefits of the vaccine are much more difficult to imagine and process. Whereas intervening to treat an existing condition is easy to understand, the notion of prevention is intangible. Paradoxically, the decrease in vaccination is the result of the success of vaccines in eradicating the respective illnesses. The benefit of injecting a substance to prevent a disease that neither the subject nor anyone around her has ever seen, such as measles, is difficult to comprehend. However, almost everyone has met a person affected by autism, and the prospect of having it is scary. General numerical illiteracy adds to the bias in risk assessment.

In the late 1990s, Andrew Wakefield, a physician at Royal Free Hospital in London, published an article in The Lancet, claiming to have found the explanation for autism in the measles virus. Initially, Wakefield reported that the measles virus was responsible for the colonic lesions seen in Crohn disease. Although this theory was soon disproved and put to rest, Wakefield was impressed by cases brought to his attention in which apparently normally developing children manifested autistic symptoms shortly after administration of the MMR triad vaccine. Despite his previous blunder with Crohn disease, he hypothesized that the measles virus had triggered inflammatory lesions in the colon, disrupting the permeability of the colon through which neurotoxic proteins reach the bloodstream and the brain, thus causing autism. Eight out of eight autistic children on whom he had performed colonoscopies ex-
hindered the hypothesized lesions, leading him to assert that the measles vaccine virus caused autism.

Even if the measles virus turned out to be on the casual path to autism, at this point, Wakefield’s findings should have already looked highly suspicious. Anybody who has ever been around autistic children and observed how phenomenologically diverse they are would have doubted that the biological underpinning of the condition affecting all eight subjects could be the same. Doubts aside, the measles vaccine hypothesis had all the ingredients necessary to become, nearly overnight, the accepted wisdom.

Reports of the presence of the measles virus in intestinal biopsies, blood, and cerebral spinal fluid sampled from autistic children quickly followed Wakefield’s report. With a simple and catchy scientific explanation secured, politicians and leaders of the powerful organizations of parents of autistic children rallied around Wakefield. Dan Burton, a US congressman and a strong proponent of the relationship between vaccines and autism held a hearing on the topic, attended and cheered by autism support organizations. The press found the perfect story: the victims (the children and the parents), the villain (the pharmaceutical industry profiting from the vaccine), and the conspirators (the scientists helping the government to hide the truth from the public). The Guardian, the Daily Mail, The New York Times, USA Today, The Washington Post, CNN, and CBS (60 Minutes) interviewed devastated parents who had witnessed their normally developing child regressing into autistic behavior soon after being injected with the MMR vaccine. In an attempt to provide balanced reporting, the media gave equal exposure to scientific evidence and opinions. Celebrity anecdotal testimony, such as that from the actress Jenny McCarthy, and news stories (Did then-British Prime Minister Tony Blair vaccinate his child?) appeared in the media alongside reports by the Centers for Disease Control (CDC) or peer-reviewed meta-analyses. Tort lawyers did not miss the opportunity to join the fray. In the United Kingdom and the United States, individual and class action suits against vaccine manufacturers were initiated, and plaintiff lawyers provided financial support to researchers backing the association between vaccines and autism.

In 2005, an investigative reporter alerted The Lancet’s editors that Wakefield’s study had been flawed by severe research misconduct, conflict of interests, and probably falsehood. After investigating the matter, The Lancet retracted the article, and the British Medical Association took disciplinary actions against Wakefield. Since the Wakefield report, any direct connection between autism and the MMR vaccine has been discredited by dozens of studies investigating the epidemiology of autism and the biological effects of MMR and the mumps virus. Decreases in the rate of exposure to MMR were not shown to correlate with similar decreases in the incidence of autism. On the contrary, although more and more parents were opting out of MMR vaccination, the rates of autism had been rising. Mumps viruses or their respective biological fingerprints were not consistently found in biological fluids or tissue taken from autistic children at higher rates than nonautistic children (for a comprehensive review rejecting the mumps virus–autism link, see Stratton et al and Modabbernia et al). However, scientific evidence notwithstanding, even if the mumps virus is not responsible for autism, surely, it was thought, another MMR component must be responsible.

To prevent contamination, the vial containing the vaccines also contains the antiseptic thimerosal, a combination of ethyl-mercury and thiosalicylate. The large amounts of mercury dumped into the oceans as industrial waste, if taken up by shellfish and consumed by humans, can cause central nervous system (CNS) damage. As autism is a CNS condition, the inevitable conclusion is that a vaccine containing thimerosal is responsible for autism. As in the MMR case, politicians, angry parents groups, charismatic proponents of the hypothesis, and a few respectable scientists teamed up to expose thimerosal as the new villain. An organization—Sensible Action for Ending Mercury-Induced Neurological Disorders—was set up; Robert Kennedy Jr offered his support; the CDC and the US Food and Drug Administration (FDA) held advisory meetings; and the New York Times Magazine and the public radio echoed the story. As with the mumps virus, no plausible argument or scientific evidence to the contrary could persuade the anti-mercury crusaders. That no parallels could be drawn between repeated ingestion of large amounts of mercury-infested food and the exposure to minimal and controlled amounts of mercury in the vaccine, or the fact that after thimerosal had been eliminated from the MMR vaccine, the incidence of autism increased rather than decreased, did not resonate with the convinced.

Not surprisingly, the alleged discovery of the etiology of autism generated a series of remedies. Vitamin
A and vitamin B supplements, minerals, antiviral and antifungal drugs, steroids, \( \gamma \)-globulin, plasmapheresis, gluten-free and casein-free diets, hyperbaric oxygen chambers, chelation, aromatherapies, and electromagnetics, made up only a small selection of the competing therapeutic choices. For example, if mercury were to be the cause of autism, then mercury-chelating agents would be the solution. Because boys are more likely to be affected by autism than girls, and testosterone binds to mercury, a drug that reduces the availability of testosterone could be the cure. Based on this theory, injections of a drug called leuprolide (Lupron)—approved for the treatment of prostate cancer and precocious puberty and used to castrate sex offenders chemically—were given to autistic children. The drug, which has serious adverse effects, was provided at upwards of $5000 per month under the pretext that the children suffered from precocious puberty. Like all other “cures,” the leuprolide one was not supported by scientific evidence, a fact that did not discourage its proponents.

Avoiding vaccination exposes the individual and the community to the risk of contracting long-forgotten diseases. The fact that the association between the MMR vaccine and autism persists in the public’s mind despite plenty of scientific evidence to the contrary raises questions about what constitutes evidence, the perception and the communication of evidence, and the relationship between scientists and the public.

The discussion of the merits and shortcomings of evidence in science in general and of evidence-based medicine in particular is beyond the scope of this essay. However, even a superficial perusal reveals that the anti-vaccine movement, like the alternative medicine movement, is walking a thin line between using evidence to support their previous beliefs rather than to consider opposing evidence.11 Through use of anecdotal cases of immediate or sharp regression into autism after vaccination, or miracle cures after unproven treatments, the anti-vaccine movement personalizes the issue.

Lacking the scientific background, in an attempt to protect their children, parents contemplating the risk of vaccine are vulnerable to omission biases by which they are more likely to take the risk of inaction than the risk of action.12 Efforts to break the link between autism and MMR vaccine by professional health care provider organizations—by employing compassionate and nonconfrontational educational means—were mostly unsuccessful, and surveys are being conducted to understand the reasons and find remedies.13 On the contrary, for parents who are inclined to reject the vaccine, well-supported scientific explanations about the safety of vaccines tend to reinforce their conviction.14 Regardless of the quality of the evidence with which they were presented, parents, as individuals or as members of anti-vaccine organizations, preferred to trust their group consensus and to adopt confirmatory evidence supporting their previous beliefs rather than to consider opposing evidence.15

The anti-vaccine movement appears to be part of a larger trend of discontent and distrust in the established preeminence of scientific evidence over impressions and opinions. A corollary to the discontent is the democratization of health-related decision making, by which stakeholders have an increasingly stronger voice over experts, as well as the dethroning of the Expert.1 While democratization of health care decision making is cheered by liberals and conservatives alike, its benefits are still to be proven. Decisions in the area of disease prevention require knowledge of the medical field involved and an understanding of statistics, in the absence of which no amount of communication skills and efforts would do any good.

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La vacunación como una causa de autismo: mitos y controversias

A pesar del significativo progreso en la epidemiología y genética del autismo, tanto la etiología como la fisiopatología de esta condición están lejos de haberse aclarado y no existe actualmente un tratamiento curativo. Mientras continúa una sólida investigación científica que intenta encontrar explicaciones y soluciones, han surgido numerosos mitos y explicaciones no científicas acerca del autismo. Los mitos acerca de que las vacunas o el mercurio están asociados con el autismo han sido amplificados por científicos mal aconsejados, eficientes pero frustrados grupos de padres y políticos. La prevención a través de la protección que brinda la vacunación o la administración de agentes quelantes de mercurio puede causar un daño real a sujetos autistas y a personas inocentes, las que ahora están expuestas a enfermedades que ya habían sido extinguidas. El florecimiento de dichos mitos es una consecuencia de la autoridad que adquiere la evidencia científica obtenida a través de la metodología científica, con una pérdida de terreno en favor de verdades y ciencias alternativas. Este artículo presenta un relato sobre el origen de los mitos en torno al autismo.

Vaccination et autisme – Mythes et controverses

Les connaissances sur l’épidémiologie et la composante génétique de l’autisme ont beaucoup progressé mais l’étiologie et la physiopathologie de cette maladie sont loin d’être comprises et il n’existe actuellement aucun traitement. Alors que la recherche scientifique sérieuse se poursuit afin de trouver des explications et des solutions, de nombreux mythes absolus et non scientifiques sont apparus. Les mythes sur l’association de l’autisme avec les vaccins ou le mercure ont été amplifiés par des scientifiques malavisés, des groupes de parents frustrés mais bien organisés et des personnalités politiques. Empêcher la protection vaccinale ou l’administration de chélateurs du mercure peut créer un réel préjudice à la fois aux autistes et à des tiers innocents qui se retrouvent maintenant exposés à des maladies qui avaient disparu. La perte de terrain de l’autorité des preuves scientifiques validées en faveur des sciences et croyances alternatives permet l’épanouissement de tels mythes. Nous rapportons dans cet article l’origine des mythes qui entourent l’autisme.