Editorial

Fear, misinformation, and innumerates: How the Wakefield paper, the press, and advocacy groups damaged the public health

On February 2, 2010, the *Lancet* officially retracted the 1998 Wakefield paper proposing a connection between receipt of the measles-mumps-rubella (MMR) vaccine and autism [1]. Prior to this, most of the co-authors on this paper had removed their names from the work – recognizing the work as flawed. In addition, the UK General Medical Council concluded that Wakefield had “shown callous disregard”, “abused his position of trust”, and acted in dishonest, misleading, and irresponsible ways in the conduct and report of this study.

Unfortunately, Wakefield had surprising success in shaping a generation of parent’s attitudes towards MMR vaccine in particular, and vaccines in general. Rarely does a research paper make so many headlines or have such large population effects on human behavior. The UK and US press quickly reported, headlined and sensationalized this report and its claims – repeatedly – over years. The public received such information uncritically and many of them, particularly those who were parents of autistic children, accepted the theory of an association between vaccination with MMR and autism. Celebrities promoted the findings as fact, and were given a bully pulpit and an aura of legitimacy by the press and other celebrities. Autism advocacy groups latched onto the study and promoted the unreliable relationship between the vaccine and autism if they were to publicly acknowledge the error of their judgments and publish (if their Editor’s allow) a full “Mea Culpa” and reaffirm their commitment to public wellbeing by committing themselves to presenting information that impacts the public health more responsibly.

The result was a tragic, heart-breaking, and embarrassing public health tragedy hard to fathom in the late 20th and early 21st century of rational thought. Fearful, mistrustful, and uncritical parents began delaying and then refusing MMR vaccines. Some took the view that the trivalent vaccine was the problem and opted for immunization with monovalent vaccines. Others did not return for second doses, leaving their children with less than effective levels of protection. Predictably, a sufficient susceptible population developed and outbreaks of these previously controlled diseases occurred in the US and the UK. Children were injured, hospitalized, and most tragically, died. Tens of millions of dollars were wasted on repeated research studies to refute Wakefield’s contention of an association between MMR vaccination and the development of autism. Time and attention were directed away from rational, scientific pursuit of more reliable and probable cause(s) of autism and toward a fatally flawed notion.

How could this have happened? In one sense it was a “collusion of co-belligerents”, unable to critically evaluate the evidence, place it into context, and appropriately respond with the best interests of the public health at heart. Some observations in this regard follow:

1. George Santayana is proved right again. Lessons from a mere 20 years earlier when pertussis vaccine was claimed to cause SIDS, and later debunked, were never learned, and hence doomed to be repeated again.

2. Sadly, we have moved from evidenced-based, to media- and celebrity-based medicine. It is apparent that some elements of the press are unable to balance reporting, risk communication, and ethics. In this instance, some have significantly tarnished their own image, and lost the trust of those they say they serve. Serious thought should be given by the public as to whether the press can self-policing their own conflict of selling their product and sensationalizing poor science – and if not, recognized as such, and remedies put into place. Freedom of speech and of the press is to be preserved – but this was clearly the equivalent of crying “fire!” in a crowded theatre. The result is that many people were and will continue to be harmed. This is not and should not, be acceptable and raises issues of liability. There may be a restoration of some of the tarnished reputation of those in the press who persistently and relentlessly supported and promoted the unreliable relationship between the vaccine and autism if they were to publicly acknowledge the error of their judgments and publish (if their Editor’s allow) a full “Mea Culpa” and reaffirm their commitment to public wellbeing by committing themselves to presenting information that impacts the public health more responsibly.

3. Autism advocacy groups and vocal parents share a significant and disproportionate blame for wasted time, money, and damage to children and the public health by their unyielding support and zealous adoption and promotion of Wakefield and his study results – despite a mountain of scientific evidence to the contrary. Indeed, as responsible researchers, in a variety of ways and with repeated studies, sought to reassure parents and family members of those with autism with science-based evidence that vaccines did not cause autism – many scientists were verbally and publicly attacked and harassed in the most uncivil manner. This is inexcusable and seriously diminishes the credibility of such organizations and individuals. Deep self-reflection would be appropriate.

4. An innumerate (the inability to use and understand numbers and mathematical concepts) press and public resonated with one another. An innumerate person or organization uses such phrases as “I don’t care what the data show… I believe…”. The answer to innumeracy is a slow and long-term one – better scientific and public education. Absent such remedies,
more tragedy will follow when the next sensational headlines appear.

5. A response from public health authorities that was “too little, too late” and was characterized by low information content, scientific jargon, and lack of innovative social communication delivery methods. As a result, clear, actionable messages were drowned out and not heard by the public.

6. Elements of the press and public ready to immediately embrace conspiratorial theories. At one meeting I attended an anti-vaccine activist was asked the question “do you really believe that everyone in the CDC, FDA, NIH, pharmaceutical companies, and all the academic researchers have pulled off a giant conspiracy to hide the truth about vaccines and autism from you?” The answer, without flinching (or apparent thoughtfulness), was “absolutely.” Such individuals and the organizations they represent do not desire nor respond to the data and weight of scientific evidence. Hence, they are not part of the solution, and are innumerable, swayed by emotion, anecdote, and perhaps conflicts of interest in keeping their own organizations and beliefs alive and intact. Evidence for this has and will continue to emerge as these entities portray Wakefield as a martyr, rather than as fatally flawed in his approach. Such organizations and individuals should be distinguished from those with genuine questions and requests for data and evidence.

Will we learn any persistent lessons from this fiasco? We have not learned from similar episodes in the recent and distant past, and we doubt it will be long before another “vaccine and some bad disease or outcome” theory is again proposed. And the cycle will repeat itself, again and again – while children and the public health suffer.

Are there any antidotes? We cannot propose any panacea, but rather steps to take us in the right direction. Questions about vaccine safety and efficacy can and should be freely raised – after all the goal is vaccine safety. Immediate attempts to investigate biologically plausible theories can often be rapidly examined using retrospective methods on large population-based databases, and passive reporting mechanisms (Vaccine Adverse Events Reporting System; VAERS) as is done in the US and elsewhere. If a safety signal is detected, basic and clinical (case-control, ecologic and prospective) studies can and should be quickly funded, carried out, and results widely disseminated. The latter point is fundamental. Vaccine safety research deserves more visibility and funding than it currently receives in the US and EU if legitimate public concerns are to be answered with credible data, and every effort – contingent with cost-efficacy considerations – should be made to insure that vaccines are safe and study results readily communicated to providers and the public. A critical new approach to vaccine safety research is that of vaccinomics and adversomics such that safety signals currently on the far fringe of, or outside of, traditional detection can be identified, and risk:benefit decisions personalized [2,3]. In addition, coordinated and winsome public health responses should occur using innovative delivery methods appropriate to the audience – including vigorous debunking of sensationalist media reports and acknowledging the limits of the data. One and only one principle should characterize all actions and discussions in this regard – truthfulness and credibility via full transparency that evokes the trust of the public MUST be the one and only goal.

Thus one sad chapter in public health and vaccinology closes and we learn some hard realities. MMR vaccines do not cause autism. Ignorance and hype do not either, but are significant barriers to discovering truth and the causes and effective treatments for autism. Let’s all do better as we move ahead. The health of us all depends upon it.

Disclosures

Dr. Poland reports receipt of research funds from the National Institutes of Health for studies of the immunogenetics of measles vaccine response. He also serves as the chair of a safety evaluation committee for non-MMR vaccines being developed by Merck Research Laboratories.

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References