The media-driven risk society, the anti-vaccination movement and risk of autismo

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Abstract  Marked changes have been seen in the epidemiological profile of infectious diseases among middle-class families in industrialized countries due to beliefs related to the risks of vaccination. These beliefs are proliferating globally due to internet sites, blogs and the influence of celebrities in the mass communication media. Due to the complexity of a cultural phenomenon of this nature, contemporary concepts aligned to the idea of reflexivity in the risk society are analyzed. The concept of a receptive media-driven society in which the announcement of danger and protection in mutual reference and contradiction are also assessed. The frequent emergence of tensions derived from cycles of utterances and baseless comments construed as symbolic “biovalues” are discussed. The persistent effect of threatening biotechnological and fraudulent utterances has influenced virtual networks for almost three decades, supporting the debate about the connection between autism and vaccines. The conclusion reached is that the processes of production of significance interconnect at various levels in which representations circulate that support communication and group identity based on historical and cultural references.

Key words  Health communication, Risk society, Media-driven society, Vaccination programs, Media and health
Introduction

In industrialized countries, we have recently seen a shift in the focus of the media and in the popular imagination, toward new threats. Just as the risks from illnesses that are controlled by collective immunization, such as whooping cough, measles and diphtheria have disappeared from their horizons (now supposedly confined to populations of the third world), they now turn their attention to the potential deleterious effects associated with new risks and ills. Almost always little understood by the common man, and frequently little-explained in their origins by science, new dangers appear on the contemporary horizon. Nationwide surveys in the USA describe recent growing distrust associated with supposed adverse side effects from immunization. Official statistics have identified and described a new pattern: the phenomenon of parents who do not vaccinate their children due to what are sometimes described as ‘philosophical beliefs’ relating vaccines to autism. Gust et al. has identified such attitudes and beliefs in 14.8% of the parents of children that were not adequately immunized, and he concluded that this would help cause a significant area of vulnerability – culturally-based – that would in turn create niches of incubation. Smith et al. made a more detailed examination of the records of 151,720 children, looking for patterns distinguishing those who did not fully immunize their children – or ‘sub-immunized’ – from ‘non-immunizers’: those who reject any type of compulsory intervention of this nature due to their belief in risks (principally those related to autism).

According to the patterns found, sub-immunized children live in adverse social/economic/educational conditions: they are children of younger mothers and single mothers with a low level of schooling, living in poor areas in large population centers. By contrast, the children that were totally non-immunized were sons (the male gender predominates, for reasons described below) of married mothers with a high level of schooling, living in neighborhoods with income above the national average, and having ample access to the mass communication media.

A large part of the ‘non-vaccinating’ couples expressed emphatic concerns about the hidden effects of vaccines, especially in relation to the neurological condition of autism. They also admitted that their pediatricians exercised little or no influence on their family decisions in this field. It is known that a significant majority of the 17,000 children not vaccinated annually live in States of the USA that do not oblige the parents to vaccinate provided they allege ‘philosophical reasons’.

It is undeniable that the emotional impact that presses upon parents responsible for children with autism is not insignificant. This stress makes relations and close acquaintances especially vulnerable to any type of discourse that attributes a sense of causality to autism – a condition which, for the imagination of society at large, is still unexplained. Physical proximity between those who share concerns, allied to the sense of causality linking vaccines to autism, can lead to situations which from the epidemiological point of view represent sources of secondary risk. The geo-economic distribution of these families is usually found to be in clusters of close neighbors – which would tend to increase contamination and transmission, both for the sub-immunized and also for the non-vaccinated – a subject which we will not deal with in this present text.

In spite of perception of so many risks, an atavistic objection to vaccination has frequently been recorded, historically, when public interventions in favor of immunization have come up against discourses evoking individual liberties. In the England of 1853, obligatory vaccination by force of a governmental act – the Compulsory Vaccination Act – gave rise to emphatic manifestations of disapproval by the upper middle class. It was taken to be an inadmissible attitude of application of force in a liberal state. English parents organized themselves in defense of freedom of choice on the subject of the immunological state of their children – and as a result there was high mortality from infections, not seen in the territories that adhered to the vaccination.

Since then, both in Europe and the Americas (with the exception of the ‘Vaccine Revolt’ episode in Rio de Janeiro at the beginning of the 20th century), intervention by the public authority has been fully justified from the ethical and sanitary points of view, based on epidemiological principles. These principles consider that the dynamic of infections is supported on an expansion of clusters of infected individuals, even those situated in regions where the diseases concerned are considered to have been eradicated. The conditions of propagation of a wave of illness, and also the speed of its transmission, are linked to the agglutination of these clusters in a critical mass of susceptible and contaminated subjects which, when it is reached, creates major obstacles to full collective immunization. In epidemiological terms, those who have not been immunized will be safer in an environment of subjects who
have been vaccinated, than the contrary situation: those who have been immunized are more vulnerable in areas in which there has not been sufficient vaccination coverage10.

In the United States, although the laws making school immunization compulsory have played a decisive role in the control of illnesses11, there are legal exceptions from compulsory application on grounds of religious beliefs in 47 States, and also exemptions allowed on ‘philosophical’ grounds (in 15 States). Counting all the exclusions, less than 1% of children of school age are not covered in the majority of the States11 – this is considered to be a safe percentage in epidemiological terms; but there is a growing number of children of preschool age, usually around age two, whose parents are insensitive to vaccination education programs and remain outside the reach of the school-based immunization laws5. These families cannot be classified as unjustly excluded from the US health system – there are no inequities involved requiring a challenge to the State, no health injustices to be confronted. This present article refers to a recent cultural phenomenon: families that deliberately exclude themselves from vaccination campaigns by reason of assumed ‘philosophical’ beliefs5. These beliefs are of a very specific, indeed peculiar, nature, and have their own specific means of reproduction. The phenomenon of the anti-vaccination networks – unreachable by campaigns of explanation, and difficult for health initiatives to contain – seems to be a product of the ‘risk society’, in an effect that is amplified by the cycles of self-referencing statements made in the today’s ‘media-referenced’ society. Discourses on the danger of the vaccination, stated and reproduced by the media that have the greatest cultural influence, will not be treated here primarily as assertions with their own logic and reason, but rather as cultural phenomena that have been born, and have reproduced, within a social web that is especially given to messages of this type. The energy of their plausibility and the force of their expansion appear to grow from complex contemporary phenomena which, for this reason, merit due study and analysis in the light, for example, of the case presented here. This requires comprehension of the central strategic role of the media, above all of the internet2, when articulated with other social practices, the dynamics of which install and structure the context and temporality of the institutions and individuals2.

In this scenario, should analysis of these new virtual spaces include observation of them as devices that read and organize new meanings? Do these new meanings, in the absence of others or of access to others, organize whole new areas of reasoning? In the case of virtual networks of ‘reflexive’ parents, has the authority of science given place to the strength of parallel-world narratives and half-theories? Are these virtual sub-systems, as new matrices of rationalities producing and organizing meaning, able to be the rationalizing base for decisions, even without meanings that are sufficiently concrete for firm decisions? Have the new patterns of symmetry and proximity between issuers and receptors made possible by the internet elevated common narratives to the status of scientific truths? Will these narratives, duly enunciated in their incompleteness and self-reference by the media, operate, for the networks of blogs and websites – with their apparent offer of organizing sources of meaning, in spite of the dubious causality of their theories – as models for action? The process of disenchantment and liberation from traditional certainties is described (though not in the Weberian sense, which points to the industrial society), above all in relation to Science, creating the turbulences of the risk society, in which a person has to co-exist with global and personal threats, emerging and recurrent, which are growing in their variety – and indeed even frequently contradictory.

**Vaccination and autism in the media**

Almost three decades ago one could already see items highlighted in the media about adverse events12 relating to immunization against diphtheria / tetanus / whooping cough, hepatitis B13,14 and it was perhaps mainly the triple vaccine (MMR in English-language countries)15 which influenced the ‘philosophical aversion’ of parents who adhered to the anti-vaccination movement. Perhaps the most controversial theme and the one that had greatest repercussion16, although sufficiently studied for more than a decade now17, involved the association between the triple vaccine against measles, mumps and German measles (rubella) – the ‘MMR’ vaccine – and autism15. Since the pioneer works of Kanner and Eisenberg19 published more than half a century ago, events related to the syndrome have become more prevalent, thanks to the instruments of diagnostics and early identification. The signs usually appear in the first year of life, and also before age three, the period of life in which the majority of vaccines are administered. The condition is two to four times more prevalent in boys16, which would tend to explain the insufficient immuni-
The position of authority that science once enjoyed would in theory last only as long as an insulating factor persists, separating scientific specialization from various forms of possibility of lay knowledge – a situation that happens only in the fields where scientific specialization still succeeds in staking its claim to some knowledge that is esoteric, in the Fleckian sense. It is plausible to imagine that the weakening of these esoteric meanings (and also the emergence and popularization of others, that are interpreted, translated and enunciated by the media), in the historic perspective of the mutations of media processes as from the second half of the 20th century, has created conditions for expansion of new risks, fears and threats in the symbolic dynamics of society. In the context of the ‘risk society’ and in the transition from the ‘society of means’ to the ‘society of media’, the former representational function of the journalistic fact, linked to the idea of truth, has begun to acquire a new meaning for the ‘reflexive’ consumer: concepts of complexity that are growing, unable to be restrained and essential to the experience of daily life. As Giddens had observed, long before the era of virtual networks, in the time of the mechanized press, the media presented themselves to us as ‘access doors’ providing consolidation of symbolic links with abstract systems that tend to expand and become more complex. From early on, the first ‘technologies of mechanized communication’ dramatically influenced all the aspects of globalization, configuring themselves as an essential element of reflexivity and of the discontinuities that compelled rupture with the traditional.

Ironically, some of the diseases that are typical of the pockets of misery and absence of healthcare are now expanding among the consumers in industrialized countries that have the greatest access to sources of information about health. For a growing proportion of these consumers, the option appears to be sufficiently clear: on the one hand, the risk of infectious diseases which they believe to be constrained to the tropical regions of underdeveloped countries; on the other, the risk of autism – an incurable neurological condition, capable of emotionally de-structuring families, and which appears to have expanded fast in recent decades due to the influence of still obscure factors. The cacophony of disinformation grows at the speed of the expansion of the list of prescriptions and proscriptions on the sites dedicated to the polemic. Epidemiological authorities attribute the recent exponential growth of measles in England, and of sporadic events confined to isolated communities to the “Wakefield legacy”, a phrase which refers to the fraudulent article published by the English researcher in 1998, which achieved ‘viral status’ through the internet, as will be discussed below. Since that year, the number of cases in the United Kingdom has risen from a few dozen to more than a few thousand annually, a figure exceeded in Europe only by Romania.

The same phenomenon has been observed and described in United States, precisely in the States that are exempt from compulsory vaccination and where celebrities dedicated themselves to publicizing their anti-vaccine position in the mass
media. A ‘body count’ website – ‘the Jenny McCarthy Body Count’ – received the name of one of the most influential and active opponents of vaccination, the US model and actress Jennifer McCarthy\(^44\). At one point in 2014 the site had counted more than 137,000 cases of illnesses avoidable by immunization, which resulted in 6263 deaths (and no case of autism provenly linked to the MMR vaccine). McCarthy’s message was always clear and direct: ‘MMR is related to the increase in the number of cases of autism’, and she demonstrates as the golden evidence the case of her son. Usually anti-MMR activists also make use of confessional rhetoric and denounce the risks to which they’re exposed under the ‘toxic overload’ of poisonous ailments combined with ‘hidden’ components in the excessive immunizations\(^45\) recommended by the US CDC\(^46\). This is true of Barbara Loe Fisher (president of the National Vaccine Information Center)\(^28\), and Curt Lindeman – a radio program presenter with a large audience – in his site ‘autismtodayonline.com’. In the American political scenario, the republican ‘creationist’ dogma seems to have its equivalent, in the territory of the democrats, in the defense of the theory of de-vaccination\(^47\). In 2005 the democrat Robert F. Kennedy Jr, also using the anti-vaccination network, published his article “Deadly Immunity”\(^48\) to support his causes\(^49\) – which in fact cost him a lot of ramifications due to incorrect information\(^28\). Kennedy Jr. had denounced exposure to high concentrations of thimerosal (a preservative used since 1930) as a risk factor for autism, although it is known that this substance does not accumulate in the organism, in contrast to its poisonous form – methyl mercury. Thimerosal had been withdrawn from preparations in 2001 and, in spite of this, there continued to be growing identification of cases of autism\(^50\).

Effects of meaning and their regulatory effect

In the contemporary world, communication technologies and their protocols circumscribe experience, and this confers a defining function on these means of access, giving them, frequently, a regulatory effect\(^51\). Kennedy’s article, and the debates incited by anti-vaccination celebrities, are making an investment in ‘effects of meaning’, employed, as Flahault puts it, in ‘symbolic complementation of the subject’\(^52\). The degree of public trust in institutions is permeated, or mediated, by these techno-symbolic organizing operations which generate innumerable new elements of risk and also their vicarious products: autism; thimerosal; testosterone inhibitors; deficiency of vitamins in gestation; and intestinal inflammatory conditions. A relation of dependency of access to such complexities was nurtured by innumerable derived problems, calling for new operations of enunciation-translation. These mediations have carried out the double function of ‘shelter, and symbolic torment’, to the extent that they announce new disorders that proliferate in today’s news reports, such as genetic diseases, the threat of ‘mad cow disease’\(^53\), and the recent media influenza pandemic\(^54,55\). Proceeding on the basis of their expansive cycles of enunciation of risks, self-referenced-ness of the translation function, and incompleteness (these factors being, indeed, inherent to the format, process, and speed of production of news) the mass communication media consolidate their position and influence by pointing to the provisional safety that they provided in that they reduce complexities and risks\(^56,57\). However, the persistent uncertainty as to the origins of autism, publicized by these processes, in contrast to full recognition of its terrible consequences, are ripe conditions leading people to seek support from social networks that flourish on the internet. In these support networks, many other faces, many other reports are mixed in, with new statements, new incomplete arguments, which only expand the shelter-torment nature of what are of course only provisional certainties\(^58,59\).

Once the links of credibility have been established between ‘reflexive’ parent-consumers, through such wide networks of websites and virtual communities, some questions arise. Is this dynamic of construction, feeding and validation of anti-immunization sentiments becoming, within these spaces, a self-sufficient circle of symbolic shelter/torment? In relation to the risk society in its confluence with the media-referenced society that now expresses itself on the internet (above all in relation to such circles of attention and reference), it can be seen that the expansion of the breadth and importance of these sites assumes a new central position in analysis of the current culture – no longer due to its representational role as a transporter of meanings, but as a ‘brand, a model, a matrix, a productive rationality, an organizer of meaning’\(^560\). From these points of view, an analysis of these new spaces would mean their observation as a device for the reading and organization of meanings which, in the event of absence or inaccessibility of others, would organize rationalities. In the case of the web networks of ‘reflexive’ parents, the primary strength
of the evidence would give place to the strength of the experiences and narratives. The rational base for decisions – which need to be exact and well-taken because they deal with the future of one’s offspring – may sometimes lack meanings that are sufficiently concrete for unequivocal decisions, if taken from these web sub-systems, which set themselves up as new matrices of rationalities that claim to produce and organize meaning\textsuperscript{60}. The internet makes possible unprecedented levels of symmetry between issuers and receivers of content\textsuperscript{61}, leading to a dissemination of common narratives closely tied to and strengthened by the most visibly impressive cases. All are linked to the networks of websites that are empathetically assertive about vaccines and their side-effects (of dubious causality), but which offer meanings which in a certain sense have an organizing function as models. Many health consumers also frequent the market of the ‘complementary’ therapies, and the modern panaceas based on statements with incomplete meanings, and residues of scientific facts, re-organized into new meanings \textsuperscript{58-62}. In this market there is a proliferation of – for example – diets without gluten\textsuperscript{63,64}, mega-doses of vitamin D\textsuperscript{65}, treatment in hypobaric chambers\textsuperscript{66}, neuro-feedback\textsuperscript{67}, enemas\textsuperscript{68}, infra-red saunas and testosterone synthesis blockers\textsuperscript{69}.

\textbf{Atavistic fears, risks and vaccination}

Expansion of the spaces of dissemination and consumption of information about health, in the context of self-references boosted by the multiple factors described above, can become impossibly challenging for the individual, who is often situated at a crossroads of conflicting versions of numerous proposed realities which demand certain and correct decisions from him with urgency. The popularization of the internet and social networks as a source of consumption of information on health has taken place in parallel with its expansion as a resource for publication of discourses and truths of multiple and frequently dissident versions and origins. For a society that is culturally structured under the shadow of risks that multiply primarily through media exposure, the demand for ‘reflexive’ decisions by all at every moment, and about all the details of daily life, takes place under conditions in which discredit and belief alternate, depending on which appeals – reflexive or otherwise – are more emphatic. Under the threat to the life of their loved ones, some parents are constantly pressured by the anxiety that expresses itself in the incessant quest for information and means of protection against ills that are multiplying everywhere. This degree of anxiety tends to create a demand, under the weight of administration of daily life and anxiety, for rationalized certainties which reduce or eliminate the complexity of decision-making. Taking as its starting point the cultural consecration of risk – made more widely known and believed by the force of the real drama of famous parents – even among initially small groups, a bio-value comes into existence which then boosts a non-symbolic market of alternative therapy artifacts, sold in the ‘vitality economy’\textsuperscript{70}, such as weight-loss diets, energy supplements and anti-cellulitis products.

According to Beck\textsuperscript{71}, the reputations of state, science and economics – the pillars of security against global risks – have been worn down, to the extent that they sometimes seem to be a type of organized and institutionalized irresponsibility. Hence the ‘self-conscious citizen’, solitary, becomes his own ‘expert’\textsuperscript{72,73}, selecting information (or versions of it) and making his own decision in the exercise of that condition under the proliferations of the imagination that are available, choosing the symbolic formats that are more acceptable or less unbearable.

In the context of health, the ancient and trustworthy vigor of formal statements is diluted in the polyphony of messages, opening wide and fertile spaces for the networks of expertise like the one described here. New vicarious tensions, in the face of badly-identified – but vividly perceived – risks, generate a quest for information in proportion to the importance attributed to the subject in their own self-referenced circles. Thus the meaning and the purpose of the lineararity, the single-voicedness and the unidirectionality of the classic concepts in the field of communication is lost. Communication having taken this form tends to place all the weight of the truths on the shoulders of qualified issuers, who struggle to give them direction as packets of evidences to those receptors who, although always alert, show themselves to be more sensitive to the security represented by known faces and their dramatic reports.

Perhaps the ‘reflexive’ options rooted in information, as described here, do not sufficiently explain to us the origin of some of the quests and interests. Perhaps the narratives of celebrities generate a boost for new searches, in turn routed in agnostic fears that finish up leading to certain sources that are more assertive (or plausible) than others. The biosciences are limited in the identification of new ill effects of toxins on the behavior of human beings due to its obvious
ethical implications. At the same time, the impact of real cases of autism, brought closer to the public via TV or the internet, is more eloquent as evidence of anything that one might wish to associate with them. Going deeper into this analysis, the options available to ‘vitality consumers’ in their subsystems of reference can be oriented not only by information, but also by representations of reality which, due to vectors which there is no space to analyze in detail in this present format, present more credibility than others. In general, going beyond the specific case under discussion here, there are hidden assertions in the media text which lead us to such evaluations, which allow themselves to be influenced by those assertions in the dialectic of meanings which the semilogists refer to as ‘modality markers’. Elements that are or are not coincident with a given reality described apply to the attitudes that the produc-er of a discourse adopts. This reality will gain the strength of plausibility, credibility, precision and factuality within a system of representations that orients, selects and stratifies the information that defines the recognizable panoramas.

Summing up, Dr. Wakefield’s article was not the irresistible force generating the anti-vaccination movement, but it gave strength to beliefs that had previously existed for more than a century, giving them at that moment the support of a technical periodical that was renowned in the biomedical field, and now have the support of web networks for explanation and mutual discussion. From that point onward, this representation began to be perceived as more tangible, and dangerously contiguous, to the extent that there was emotional involvement, empathy with cases that were close to the receiver either because of acquaintances or celebrities, and the inter-link-ing of health consumers in the world of the web. Summing up, Wakefield, among others, gave a factual and analytical form to pre-existing representations. This gave strength to (but did not originate) reproductions of a representation on which a scientifically validated reality was constituted and expanded in sub-systems of meaning. From the Fleckian point of view, a ‘system of reference’ may support this pseudo-scientific fact through which multiple ‘passive connections’ and ‘active connections’ began to come into balance and to develop, generating a type of knowledge, and derived sub-products, that were the result of a human cultural activity in its interactions with the social and the natural. The meanings that are enunciated, which are self-referencing and incomplete in this market, offer expectations of salvation or solution of problems, which ensures that they have cultural impact (as well as commercial success) among those who have no other hope. The anti-vaccination movement began to be anchored in biotechnology, gaining a concrete meaning and an essential bio-value which, in the continuous production of ‘realities’, constituted itself as one more piece in a complex universe of representations that transcends the universe of reflexivity – one more sub-system of this cultural ‘whole’. It is, thus, perceived that the processes of production of meanings, in contrast to the primordial Frankfurtian logic, are interlinked with various levels in which ideas circulate: the representations that sustain communication; the identity of groups; and the historic cultural level of the public imagination as a cumulative production of the ideas that circulate as references that are always susceptible to assignment of new meanings.

Conclusion

The latent emphasis on lay sociological and political discourses refers to a new form of relationship with health professionals. The new consumer, instructed by a ‘reflexivity’ linked to values rooted in consumerism, takes a point of view of a single rational option when confronted by the alternatives of a ‘dilemma-causing market’ – a situation which can be said to be at the same time healthy, and lethal. The consequences of the irreversible options in this field can be converted into insupportable blame when one has full access to the information in PubMed and Google. Few attenuating factors remain for forgiveness of decisions taken in a heedless fashion by ‘reflexive’ parents. The health consumer’s reasoning takes place today in conditions of growing credibility for the internet in questions of protection and maintenance of a healthy life in the face of innumerable new bio-threats that present themselves. From the point of view of consumers of health information, in the vacuum of certainties, it is more prudent to unite oneself with celebrity faces and biographies that sound familiar than, on the contrary, orient oneself by the averages of official statistics, which by nature are indeterminate and intangible.

The picture is one of colonization of the media by sources of meaning that are self-validating, often about ‘bio-values’ – and they achieve this communication by filling of empty spaces. Background-noise micro-signals, and rumors, about risks, amplified by the ‘celebrity effect’, frequently cause debate, generating a cycle of
statements, self-references and incomplete affirmations, which promote content to occupy the spaces reserved for the truths that have the appeal of a more rigorous basis. As an example, this was the route taken by the cycle of statements that involved Kreutzfeld-Jacob disease, initially a circuit of information exclusively of interest to specialists – but which was converted into 'Mad Cow Disease', by the journalistic phraseology of lay publications. As such it was promoted to the vicious circles of self-referencing content – in a parallel to the epidemic whose worldwide economic and political repercussion is still remembered. In the specific case of collective immunization, these circles of attention seem to be amplified in time and in space – from their origins in the nineteenth century until the present globalized scenario. Transcending the concept of the information society, in the context of what is now the media-referenced society – and the risk society – it is concluded that the threat to the health or physical integrity of children overburdens those parents who no longer permit themselves to have doubts. They then, reflexively, cannot allow themselves to make mistakes, in the face of the unresolved questions – which lead them to the widely accessible information resources which are, however, mutually dissonant. They feel urged to a decision, under the self-imposed imperative of categorical certainties apparently expressed in unison, between options which perhaps lead to them taking either acceptable and responsible positions in relation to imminent risks, or others that could perhaps cause irreversible consequences.

Collaborations

PR Vasconcellos-Silva, LD Castiel and RH Griep participated equally in all stages of preparation of the article.

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