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Abstract

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Reference


DOI : 10.1111/irv.12090
PMID : 24034495

Available at:
http://archive-ouverte.unige.ch/unige:38857

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Unresolved issues in risk communication research: the case of the H1N1 pandemic (2009–2011)

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The 2009 H1N1 pandemic had considerable impact on risk perceptions, vaccination campaigns, and global health governance. In this context, risk communication issues have been probably the most puzzling and the least understood in retrospect. This article reviews the current knowledge on the following issues: risk and pandemic perceptions; vaccination perceptions and practices; rumors and rumor propagation; and health risk communication. It also highlights the research gaps in these areas that remain to be further explored in the future.

Keywords: Global health, health risk communication, pandemic, risk perception, rumors, vaccination.

Please cite this paper as: Barrelet et al. (2013) Unresolved issues in risk communication research: the case of the H1N1 pandemic (2009–2011). Influenza and Other Respiratory Viruses 7(Suppl. 2), 114–119.

Introduction

In the aftermath of H1N1, several questions have been raised, by government officials, health experts and practitioners, as well as by members of the public, and members of parliament. The management of the global response, the conditions under which vaccination campaigns have been launched, alleged conflicts of interest between government agencies and pharmaceutical firms, distrust of official messages, and emergence of recurrent rumors in the media and over the Internet brought to light challenges that health officials at all levels typically have to face during and after such pandemic episodes. Considering the large and contrasting impact of the pandemic, this review aims at contributing to the description of lessons to be learned for future pandemics or similar global events, from the vantage point of social sciences.

Methods

This review that has to be understood as a snapshot is based on a comprehensive search of articles published from 2009 to mid-2011 in the following databases: Sociological Abstracts, AnthroSource, Cairn, Persée as well as Google Scholar. On purpose, it does not include the PubMed database, as the focus was deliberately on social sciences productions. Furthermore, the following social sciences journals have been systematically reviewed: Sociology of Health & Illness, Social Science & Medicine, Health, Risk & Society, Journal of Risk Research, Journal of Health Communication, The European Journal of public health, Risk Analysis, Medical Anthropology and Cultural Anthropology. The search was conducted using the following terms: “risk perceptions,” “vaccination practices,” “rumors,” and “risk communication,” as standalone entries or combined with the terms “flu,” “influenza,” “H1N1,” and “pandemic.” Two further discriminating criteria were used to select the references: the articles had to be (i) written by social scientist scholars and (ii) published in a peer-reviewed scientific journal.

Results

We identified 60 articles fulfilling the search criteria. These articles can be divided into the following nonexclusive categories: case studies on H1N1 (16 articles), case studies on H5N1 (11), case studies on seasonal flu (2), case studies on other diseases or a mix of case studies (7), studies on other public health risks (3) (i.e., mobile phone and climate change), studies with a predominantly theoretical orientation on risk communication, Internet or rumors, with references to different diseases (24). Methods used in these articles range from qualitative in-depth interviews, focus groups, or public consultations, ethnographic studies, quantitative surveys, literature review, media discourse analysis, social media analysis, and government documents analysis. The results are presented along four sections: risk and pandemic perceptions; vaccination perceptions and practices; rumors and rumor propagation; health risk communication – covering
main issues regarding the tensions that developed between the public and health authorities around the management of H1N1.

Risk and pandemic perceptions

Case studies on H1N1, H5N1, and risks associated with mobile phones provide important insights on risk perceptions in general and pandemic influenza perceptions in particular.

Among the general public, H1N1 was often associated with traditional seasonal flu; therefore, H1N1 risk was thought to be low. A Turkish study stresses, however, the coexistence of mixed perceptions about H1N1 influenza: some respondents perceived it as “a fatal disease that creates anxiety and brings up the idea of death” and that could affect their own health, while others saw it as a disease having similar symptoms to seasonal flu. Because H1N1 was perceived to be associated with the seasonal flu and the mortality level was considered as low, risks were more often associated with vaccination than with the virus itself. Segments of the population perceived the H1N1 pandemic as being artificial, an example of “considerable difference between the physical reality of health as described by authorities and the reality perceived and interpreted at the social-individual level.”

Several studies report public distrust in different actors of the pandemic crisis, in particular governments, the media, pharmaceutical industries, and national health authorities. Nevertheless, a report from the European Commission in November 2009 shows that health professionals were the most trusted sources of information among EU citizens. Media’s impact on risk perceptions is widely discussed in the literature. A survey on 3000 people in Sweden shows that daily listening to public service radio and morning newspaper reading were not associated with fear and concern, while daily tabloid reading and television watching made people more concerned. In addition, respondents reading tabloids trusted authorities less than those watching public television, reading morning newspaper, or listening to public service radio. A German study reported that watching 5–10 minutes of critical websites daily amplified fear about vaccination and reduced anxiety about the virus.

Numerous case studies on H1N1 and H5N1 illustrate how an “Other” was blamed for being the cause or the vector of the flu producing the stigmatization of specific individuals or collectivities. One paper states that “fighting against any disease or finding a solution to a social problem is in fact related to knowing how members of a society perceive it.” Such a blaming process seems to appear in every new crisis. Indeed, developing countries are often collectively described as “both the source and carrier of disease.” During the H1N1 crisis, Mexicans were depicted as “unhygienic subjects and circulators of disease.” Due to this “geography of blame,” the disease’s name in itself carries a risk of blaming. Mexicans were blamed for the “Mexican flu,” pigs were blamed for the “swine flu,” and birds for the “avian flu.” These processes affect targeted people and can subsequently lead them to reject health authorities’ guidelines.

Industrial-scale agribusiness has also been blamed as a potential source of H1N1 or H5N1 dissemination: “Public interest groups and NGOs openly questioned the lack of surveillance on the meat industry and factory farming, which are potential root causes of both H5N1 (avian flu) and H1N1. For example, some considered that the “free range birds” were vectors of the disease, while others blamed “industrialized farming” practices in general.

Vaccination perceptions and practices

The selected literature encompasses studies on the general public views on vaccination, the health professionals views and practices, and the authorities practices and statements on vaccination organization and distribution. In our review, most studies are focused on pandemic or seasonal flu vaccination practices, while a few examine other diseases (i.e., polio, tetanus) or address vaccination as a secondary topic. Two studies report on collaborative and community interventions that increased vaccination coverage.

Public health officials seem to have been disconcerted by H1N1 vaccination rejection. However, such phenomenon has already been described (i.e., MMR, tetanus, polio) and is not specific to influenza. Indeed, large parts of the population in different countries rejected H1N1 vaccination including France, Canada, and Turkey. Several studies address H1N1 vaccination failure: The 2009 controversy targeted alleged conflicts of interests between pharmaceutical industries and nation states or international authorities as well as the existence of a suspicious “hidden agenda.”

Among the general population, factors that promoted H1N1 vaccination or vaccination intentions were as follows:

- Previous experience of vaccination against seasonal flu.
- Access to scientific information.
- Self-estimated knowledge about vaccination.
- Medical staff consulting.
- Concerns about the virus and its consequences.
- Trust in state authorities.

Factors that reduced H1N1 vaccination or vaccination intention were as follows:

- Fear of vaccine side effects (in particular, fear of mercury and adjuvants).
- Perception of a lack of information on vaccine side effects and a lack of vaccine testing.
• Lack of trust in authorities.\textsuperscript{7,9,36}
• Attitude (or comments) of opinion leaders (i.e., the prime minister of Turkey refusing to vaccinate for H1N1 had a major impact on vaccination in this country).\textsuperscript{5}
• Consulting Internet\textsuperscript{5} and particularly vaccine-critical information websites.\textsuperscript{26}
• Risk of vaccination perceived as higher than risk associated with the virus.\textsuperscript{7}
• Vaccine perceived as not useful.\textsuperscript{5}
• Being a woman (suggesting the existence of a gender effect).\textsuperscript{29}

Two studies report on health professional vaccination practices.\textsuperscript{5,33} Ideas related to conspiracy around H1N1 vaccine and worries about the vaccine secondary effects were also found among healthcare professionals.\textsuperscript{24} Their reasons to get vaccinated against H1N1 included protection of patients and of other people around them.\textsuperscript{33} Reasons to not get vaccinated included lack of vaccine testing (new vaccine), fear of vaccine side effects, perceived influence of pharmaceutical industries financial interests, being female and a nurse (in comparison with being a male and a medical doctor).\textsuperscript{33}

The impact of fear and worry on individual behaviors and their use in risk communication are assessed. A French study, early in 2009, states that without a drastic increase in the perceived risk, the proportion of the population actually vaccinated would remain very low and mainly concentrated among older people.\textsuperscript{9} However, other studies reject or nuance this idea that fear or anxiety increases vaccination coverage.\textsuperscript{5,16,31,35} A South Korean study concludes that fear-based programs on the Internet improved education on influenza more than humor-based ones; however, none of the programs led to behavior change.\textsuperscript{16} A Turkish survey shows that fear of influenza did not increase vaccination, but modified daily behaviors (i.e., increased hygiene).\textsuperscript{5} A French study concludes that the use of fear in H1N1 prevention messages conducted people to avoid sources of information, to understate risk of catching H1N1, and ultimately to reject vaccination.\textsuperscript{35}

Some studies note that failed forecasts and inadequate organizational responses to specific events prior to H1N1, notably hurricane Katrina\textsuperscript{2,4}, the 2008 economic crisis,\textsuperscript{12} and previous “sanitary crises” in France\textsuperscript{24}, have paved the way for a lack of trust in state, international institutions, or pharmaceutical companies.

A number of case studies emphasize the importance of trust in health authorities. Many Swedes trusted the way their national authorities handled the pandemic, which led to the highest vaccination rate in Europe.\textsuperscript{6} By contrast, the French population trusted their authorities less and the vaccination rates remained low.\textsuperscript{29} The loss of confidence in authorities and in the media, linked to perceived conflicts of interests, contributed to the rejection of nation state strategies, in particular mass vaccination.\textsuperscript{7} According to the Swedish study, trust in authorities largely counterbalanced people’s worries and concerns about the vaccine.\textsuperscript{6}

Two studies address correlations between the social positions of individuals and their perceptions and practices regarding vaccination.\textsuperscript{6,30} A Swedish study establishes that “people with high capital, including a specific pattern of media consumption, were characterized by high trust in the authorities, as well as low concern for the influenza. Also, this was the group with the highest vaccination willingness. People with low social capital, and another type of media consumption, showed a reverse pattern. Among these people, trust in the authorities was lower and their concern for the virus was higher than average. The willingness of this group to get vaccinated was also lower.”\textsuperscript{6} A study on nurse vaccination practices in Switzerland suggests that a positive social identity and a feeling of recognition combined with professional stewardship could lead to higher rates of vaccination.\textsuperscript{30}

**Rumors and their propagation**

A small number of studies address the topic of rumors; they include theories on rumors,\textsuperscript{24,40} case studies of rumors around SARS\textsuperscript{41} or vaccination campaigns,\textsuperscript{36} and references to rumors as a secondary topic.\textsuperscript{2,3,27}

Public health officials have been challenged by the number and extent of rumors in the context of H1N1. Rumors respond to a need for information\textsuperscript{40} and can be described as an “act of intensified collective information seeking.”\textsuperscript{41} Rumors especially emerge when the public does not trust the “institutionalized channels of communication.”\textsuperscript{41} Propagation of rumors around possible causes of infectious disease are not new; motives and proclaimed goals of public health interventions are also a common theme of rumors.\textsuperscript{36}

Surrounding H1N1 emergence and public health officials responses to it, many narratives were labeled as rumors and sometimes as conspiracy theories.\textsuperscript{5,41} These circulated widely among different social circles, including elites, health professionals, and the general population.\textsuperscript{41} Media, Internet, SMS, blogs, word-to-mouth served as vectors of circulation.\textsuperscript{41} A Chinese study on 2003 SARS rumors illustrates how mass media can serve as a tool for rumor circulation as well as for denial of rumors and counter-rumor circulation.\textsuperscript{41}

Rumors are usually understood by public health professionals as “untrue” narratives, “misunderstandings,” and “obstacles” to official prevention programs. They consider rumors “as failures in communication, to be rectified by the provision of more accurate information.”\textsuperscript{36} However, it is argued that: “(e)ven when ‘accurate’ information is provided, the rumors will continue, because they express a social reality, which no amount of alternative information can change.”\textsuperscript{36}
Rumors typically emerge in a context of asymmetries of power.\textsuperscript{24,36} As access to knowledge and definitions of what is true or not rest upon limited groups of experts,\textsuperscript{3} those left aside develop alternative ways to express their opinion. Rumors provide parallel information, especially when official communication is limited to a top-down approach.\textsuperscript{40} Therefore, propagating rumors on the Internet might be considered as a competing “open-access space for the circulation of knowledge.”\textsuperscript{53} These complex situations call for a multiplication and validation of opinion sources rather than for a unique and official position.\textsuperscript{2,3,42,43} In H1N1 context, rumors might have served this function of multiplication and validation.

As another example, a case study on a rumor in Nigeria and Cameroon reports on the isomorphism of family planning campaigns, regulating fertility and promoting contraception, with vaccination campaigns. The fact that they were held by the same institutions probably played a role in the rumors establishing tetanus and polio vaccine as a source of sterility.\textsuperscript{36} This isomorphism process might apply in other contexts. More research is therefore needed to understand how culture influences rumor propagation.

### Health risk communication

Selected studies analyze communication in case studies on H1N1, H5N1 or another health risk event\textsuperscript{5,7,12,14,20,23,29,31,35,37,43–49} or encompass different case studies.\textsuperscript{2,26–28,50–56} Building trust is often described as a crucial component of risk communication.\textsuperscript{7,14,27,47,49,52,54} Recent textbooks\textsuperscript{28,50} emphasize that communication is a dynamic process and therefore that communicators should develop a two-way process engaging the public as a “real partner,” promote a dialogue and build a relationship with diverse publics.\textsuperscript{7,27,37,39,47,49,51} To construct effective risk communication, the knowledge, concerns, values, interests, and priorities of the targeted populations should be identified upstream, as well as their risk perceptions and more broadly their cultural values.\textsuperscript{7,47,51}

However, a two-way communication process has yet to be applied more widely. The focus on accurate “information” demonstrates “how little examined the social and cultural dimensions of pandemics are or how to express potential risk and uncertainty in a meaningful way to people who are not epidemiologists or health educators.”\textsuperscript{28} It is further claimed that “linear, vertical bio-communicable models that picture laypersons as ignorant recipients of expert knowledge still predominate.”\textsuperscript{2}

At the same time, an in-depth study of public consultation in a US vaccination-related policy project uncovers an instrumentalization of public consultation toward a “simulation of a social verdict.”\textsuperscript{44} If communicators are not willing to rethink their assumptions and to genuinely include public insights, then organizing consultation makes no sense. However, another American study examining a consultative bottom-up approach involving stakeholders from the beginning\textsuperscript{47} concludes that it led experts and authorities to modify their assumptions and helped to prepare a risk communication strategy drawing on local knowledge.\textsuperscript{47} Taking into account online comments on dedicated websites is also a concrete (and economical) example of public consultation.\textsuperscript{7}

Other studies emphasize that public opinion is not solely built from institutional messages\textsuperscript{31} but also includes shared testimonies, advices, discussions with family, friends, neighbors, family doctor, and professionals, as well as TV, newspapers, the Internet (databases, Google, participative spaces, that is, forums, Facebook, Twitter).\textsuperscript{5,6,26,29,32,42,43,58} However, it is also important to stress that, even though the Internet and social media are widely considered as new information sources, many actors do not use them.\textsuperscript{31}

Furthermore, the Internet is a powerful tool to extract opinions\textsuperscript{1,7,31}, but it is much less effective to organize a dialogue and “the contemporary illusion” of the Internet as a democratic public space should be questioned.\textsuperscript{31} The Internet is therefore an ambivalent tool because it can be used by opposite groups for a similar purpose, for example, mutual surveillance (by authorities on civilians and the opposite).

“Influenza surveillance (…) illustrates that pragmatic dimensions of production and circulation of health knowledge are changing (…).”\textsuperscript{32}

### Discussion

This review of social science literature published during and in the direct aftermath of H1N1 indicates some important findings to take into account in public health campaigns addressing pandemics in particular and risk issues in general. In addition, this review also shows important gaps that should be addressed by further research.

It is now established that risk perceptions vary across time, social groups, cultures, and countries. We also know that they are influenced by emerging patterns of information gathering and dissemination (increasing importance of social media; competing sources of information; possible substitution patterns; possible information overflow in some parts of the world). However, the critical variables that dynamically influence risk perceptions in a context of competing information sources have yet to be better understood.

Social resistance to vaccination is an enduring phenomenon that should not be downplayed by public health officials. Better understanding the ambivalence of the public is important to help designing effective vaccination campaigns. However, the role of healthcare professionals (including nurses and doctors and allied healthcare professionals) is also central and their strategies and perceptions toward vaccination should be further investigated.
A study affirms that “the place of rumors in the circulation of knowledge about health remains under-theorized.”

It is not yet established at a more general level whether specific cultural characteristics have an impact on rumors. More research is needed to understand how culture influences the elaboration and propagation of rumors. Competing narratives (official statements and presentations, rumors, conspiracy theories, alternative worldviews and explanations, urban legends, hoaxes, etc.) about public health crises always coexist in the public sphere. Their emergence patterns and relative impact on risk perceptions have yet to be better understood.

Still too few studies report on how health authorities plan, develop, implement risk communication strategies. It is crucial to further this knowledge in the context of fostering learning through past experiences’ processes. This organizational learning should include successes, as well as past errors, misunderstandings, obstacles, shortcomings, and public criticism related to risk communication.

Conclusion

This limited snapshot review would surely benefit from being further articulated with earlier studies. However, our review suggests that many risk communication issues are still unresolved. Unless systematic and in-depth research is promoted, current puzzles will remain in the way. Cases studies do exist yet a theorization, allowing collating their partial results is still missing. As a result, lessons learned are difficult to draw due to the absence of a comprehensive explanatory framework.

Therefore, three main research gaps emerged from our review:

1. How risk perceptions are dynamically influenced in an era of competing sources of information? Risk perceptions vary across time, social groups, cultures, and countries. They are influenced by changing patterns of information gathering and dissemination (emergence of social media; competing sources of information; possible information overflow in some parts of the world…). Trust building is a key aspect of risk perceptions. However, the critical variables that dynamically influence risk perceptions in a context of competing information sources have yet to be understood.

2. How do competing narratives frame risk perceptions? Competing narratives (official statements and presentations, rumors, conspiracy theories, alternative worldviews and explanations, urban legends, hoaxes…) about public health crises coexist in the public sphere to various degrees depending on the crisis. Their emergence patterns and relative impact on risk perceptions have yet to be understood.

3. How do public health authorities manage to articulate risk communication theoretical principles and implementation in the field, which carry scores of surprises? Very few studies report on how health authorities plan, develop, implement risk communication strategies.

However, this knowledge is important to collect in the context of fostering learning through past experiences’ processes. This organizational learning, at all levels (international, national, local), should include successes, as well as past errors, misunderstandings, obstacles, shortcomings, and public criticism related to risk communication. The complexity and scale of current risk issues clearly call for the specific contribution that social sciences can make to the governance of public health.

Conflict of interest

The authors have no potential conflicts to declare.

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