Breach of Information Ethics and Medical Professional Ethics during SARS Epidemic in Japan

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ABSTRACT

SARS has received much attention not only because of its contagious nature and high fatality rate, but also because facilities for treating patients were the very place of infection. According to the Japanese mass media, the only case of SARS in Japan was one Taiwanese tourist. However, the official announcement was misleading. The Japanese SARS Expert Committee introduced the term "confirmed case" in their definition without describing its diagnostic criteria, and as no method of confirming SARS was available, no cases were considered to have occurred in Japan. Thus, the number of SARS cases remained at zero in the mass media and on the WHO website, although the number of suspected and probable cases reported on the government website were increasing. This withholding of information was made possible by collusion between the triad of medical experts, mass media and health officials. Fortunately, during the 2003 SARS epidemic, no secondary cases occurred in Japan. However, had secondary cases occurred, such withholding of information would have had disastrous consequences domestically and internationally. It is hoped that medical experts, media reporters and health officials will in future behave in accordance with their professional ethics.

Introduction

After its first appearance in February 2003, SARS (severe acute respiratory syndrome) spread rapidly around the world and affected many people in a short period. Transmission of the infection was particularly severe within hospitals and many health care professionals were infected with the disease at their work places. Thus, SARS has received much attention not only because of its contagious nature and high fatality rate, but also because facilities for treating those with the disease were often the very place of infection. Naturally, fear and even panic were observed among the public in many countries and Japan was no exception in this regard.

There was considerable confusion among the public and health care sectors in the light of news reports from abroad, although the official number of SARS cases remained at zero in Japan. Children who returned from the affected area were ordered by the local authorities to stay at home, even if they had no indication of SARS or contact with SARS patients. On the other hand, 77 tourists who stayed at a SARS-affected hotel in Hong Kong were not followed up on returning to Japan on account of privacy concerns. These are only a few examples of the numerous ethical issues arising during the SARS pandemic. The aim of this article is not to deal with those issues already described extensively (1-5), but to focus on the ethical issues regarding control of information in Japan during the 2003 SARS epidemic.

The SARS Epidemic in Japan

According to the Japanese mass media, the only case of SARS in Japan was that of a Taiwanese tourist. This seems curious if one considers the high volume of travel between Japan and such countries as China and Hong Kong. Indeed, the official announcement was fraudulent, based on distortion of the WHO definition of SARS by the SARS Expert Committee set up by the Japanese Ministry of Health, Labour, and Welfare (Table).

While the Japanese definition of "suspected case" was identical to that of the World Health Organization (WHO), the SARS Expert Committee translated "probable case" as "possible case" in Japanese. Both "suspected cases" and "possible cases" were to be reported to the SARS Professional Committee. In addition, the Committee listed "confirmed case" among their definitions (6), a term that does not appear among the WHO definitions (7). In any case, the causal agent had not been identified and there was no method of confirming SARS during the early phase of the pandemic, although an etiological virus was later identified and serological diagnostic methods subsequently became available. What the Japanese experts meant by "confirmed case" was not clear, because they did not provide criteria for confirmation of cases. Furthermore, the Japanese SARS Expert Committee considered that recovery ruled out a diagnosis of SARS; in other words, in Japan, only a "possible case" with a fatal outcome would have been considered SARS.

However, the fatality rate was 15% on average, therefore the disease was not always fatal. As no fatalities occurred among the probable cases (possible cases), numbers of confirmed cases of SARS remained at zero in Japan.

While it is not clear why the Japanese SARS Expert Committee distorted the definition of SARS, it is possible that they were attempting to reduce the impact of SARS-related fear on the public by pretending that no cases SARS had occurred in Japan. A paternalistic attitude was also evident in the mistranslation of the word "probable" as "possible," with which the impression of seriousness was lessened. In terms of international consequences, it was very fortunate that no secondary cases of SARS occurred in Japan. If secondary cases had occurred, there was a possibility that the withholding of SARS information to the WHO and the general public might have had disastrous effects on the SARS pandemic.

The original figures for suspected cases and "possible cases," which were reported from nationwide hospitals, were available on the government website of the Japanese Infectious Disease Surveillance Centre (6). As explained by the health Ministry, this website was accessible to the general public, including journalists and media reporters (8). However, the general public was notified numbers of "confirmed cases" via the mass media, which only published official announcements by the SARS Expert Committee. Thus, the number of SARS patients remained at zero in the media, although the number of suspected cases and probable cases (possible cases) were increasing daily on the government website (6). As the SARS Expert Committee do not intend to conduct serological investigations, the actual prevalence of SARS in Japan remains unclear.

Reporting of information to the WHO

China was repeatedly criticized over its failure to reveal information on SARS; this lack of disclosure was considered to have impeded domestic and international measures to control the epidemic (9,10). Despite having seen from the criticism of China that information disclosure was vital for infection control (11), the Japanese Expert Committee continued to report the number of "confirmed cases" as zero to the WHO, and actual figures of probable cases (possible cases) were not notified.

The WHO was later informed about the withholding of SARS information by a whistle blower (12) and forced the Japanese government to report original figures of probable cases (possible cases). The delay was said to have frustrated members of the WHO (12), as accurate data on the spread of SARS was regarded as crucial in order to prevent further pandemics. However, the Japanese SARS Expert Committee maintained their definition of "confirmed cases," continued to define recovered probable cases (possible cases) as not having SARS and deleted these from the list of SARS patients provided to the WHO. Thus, the official figure of SARS cases remained at zero domestically and internationally. Presumably, the WHO did

not realize this additional trick by the Japanese SARS Expert Committee. Later communications between Japanese doctors and the Japanese health Ministry could not clarify the true nature of this obstruction (8,13).

The Triad of Medico-Aristocrats, Media-Aristocrats and Bureau-Aristocrats

It was extremely fortunate that no secondary cases of SARS occurred in Japan, thanks to intensive preventive measures by staff at hospitals where probable cases were admitted. However, if an epidemic had occurred, the situation would have been much worse than in other countries including China because the Japanese authorities withheld SARS information from the public as well as from the WHO.

Why was such a potentially disastrous attitude employed in Japan? It cannot be explained by the language barrier alone, because the number of SARS patients as accurately defined by WHO criteria was posted on the government website. Moreover, if any of the SARS Expert Committee, health officials or mass media had disclosed the available data on this website, such a problem, which was specific to Japan, would not have occurred.

In an attempt to explain this behavior, the author will discuss the strong triangular relationship among medical experts, mass media, and bureaucrats, who are termed medico-aristocrats, media-aristocrats and bureau-aristocrats, respectively. The term "aristocrat" is used, because these individuals seem to enjoy their status as members of the distinguished elite, and are highly unlikely to give this position up. It is postulated that this triad exerted strong pressure on each other resulting in suppression of rational behavior and withholding of information on SARS.

Medico-Aristocrats

Why the Japanese SARS Expert Committee produced a definition of a "confirmed case" in a situation in which there was no method of confirming SARS can only be speculated upon. Previously, the AIDS Expert Committee behaved very similarly in adding an extra criterion for diagnosis of AIDS to the international criteria. When the first case of AIDS (defined according to the international criteria) appeared in a Japanese hemophiliac, the Committee concluded that the patient did not have AIDS because the Japanese criteria for the disease were not fulfilled. They did not acknowledge the first AIDS case in Japan until a patient contracted the disease by the sexual route. This behavior was said to have followed from instruction by health officials who tried to reduce the impact of AIDS appearance for fear of complaints about their health policies, which had delayed the introduction of safer blood products. Delayed recognition of the first AIDS patient further impeded measures to prevent the spread of HIV infection among Japanese hemophiliacs. This chain of events eventually came to light. Thus, members of the Expert Committee, health officials, and company executives were charged with negligence regarding the use of risky

blood products, and some individuals were convicted on this basis (14,15,16).

In the case of SARS, health officials had no conflict of interest in reporting SARS patients as defined by the WHO criteria. Therefore, the SARS Expert Committee was likely to have acted according to their own volition, possibility on the basis of paternalistic attitudes as mentioned above. Another factor is the level of infectious disease medicine, which is not satisfactory in Japan. One of the most telling illustrations of this is an issue of the prophylactic use of antibiotics. In 2002, Japanese doctors disseminated "up-to-date information" for prevention of surgical site infection to Japanese institutions (17). However, their "up-to-date information" was the issue under extensive investigation and discussion outside Japan during 1960s (18). The guideline for prevention of surgical site infection derived from those studies had been published 20 years previously and had long been the basis of established practice overseas (18). This illustrates the less advanced level of infectious disease medicine in Japan compared with other countries.

Japanese health officials had access to information from the WHO and could therefore have rejected the criteria set by the SARS Expert Committee (8). One possible explanation for their failure to do so is the lack of peer review in Japanese society; it is considered rude and against Japanese etiquette to criticize others. This system lets distinguished medical experts enjoy their privileged status without being criticized. The worst example of this may be that of doctors in Unit 731 of the former Japanese army who performed vivisection on wartime prisoners in China (19). The doctors involved in these events were not put on trial, but instead went on to become professors and even a medical school president (19). It is unfortunate for these Japanese doctors that the opportunity for genuine reflection on their behavior was missed, and it is even more so for the public, who have suffered as a result of a series of embarrassing and tragic mistakes (15). A sound system of peer-to-peer criticism is essential to improve the quality of medicine for both doctors and patients.

Media-Aristocrats

The number of SARS patients according to WHO definitions was posted on the government website and was freely accessible (8). Hence it is natural to assume that, media reporters knew the actual figures. However, they only reported the official figure of zero SARS cases provided by the SARS Expert Committee. Their behavior may be partly derived from the Japanese tendency to avoid taking initiative (20). In any case, it seems that none of the media dared to make this "scoop".

More importantly, a treaty is in place between the mass media and the health Ministry, which assures the media first access to information from health officials. For media reporters, this system may represent an easy way of obtaining information from the government. However, the news delivered by officials may be "brushed up" prior to media briefings, and because Japanese media reporters are accustomed to

waiting for news from officials, they are unlikely to closely examine this information once delivered. This is exactly the phenomenon observed in the SARS epidemic in Japan.

When considering inherent problems in the Japanese media, a further factor that must be mentioned is the Kisha Club (press club). The Kisha Club, a voluntary institution maintained by the Japanese media industry for over a hundred years. Established at all levels in Japan, from local to central government, the Kisha Club was originally intended to promote freedom of the press in accessing government offices reluctant to disclose information. The major problem with this club is its highly exclusive nature; non-members are not allowed to be present at media briefings by officials. The long-standing bond between officials and media reporters has turned the Kisha Club into a kind of friendly social membership club; its original aim has been eroded or corrupted. It has been repeatedly criticized by journalists inside and outside Japan as providing a means of sharing benefits among its member officials and journalists (21). When the author leveled this criticism in a newsletter of the Medical Journalist Society in relation to withholding of information relevant to the SARS epidemic, no response was received (22). Nowadays, the Japanese mass media often accused of doctors of a lack of transparency (15). However, the mass media themselves have no intention of opening the door to non-members, as media and officials seem happy in this system enjoying their privileged status.

Consequences of the Triad of Medico-Aristocrats, Media-Aristocrats and Bureau-Aristocrats

Regarding the final arm of this triad, bureau-aristocrats have been described in relation to medico-aristocrats and media-aristocrats. The three arms are tightly interconnected, preventing criticism from outside. The triad had the good intention of avoiding fear and panic among Japanese people; however, the measures that were taken had quite the opposite consequences. Japanese local authorities disinfected underground trains when they discovered that the infected Taiwanese tourist had used them. This action was totally irrational, because it was performed long after the contagious period had elapsed. Similarly, hotels where the tourist had stayed were forced to remain closed even after the contagious period was over. Although health officials claimed that they had provided the public and local officials with enough information (8), the principal source of information was the mass media. The general public and local health officials therefore had to act on insufficient information, and consequently could not respond appropriately.

Hence, paternalistic attitudes by members of the triad only made the situation worse. Because of the highly contagious nature of SARS, preventive measures imposed by such insufficient information would have been disastrously inefficient if secondary cases had occurred. If any of the three arms of the triad had acted

sensibly, no such withholding of information would have happened. In this sense, medical experts and media reporters may be primarily responsible for the cover-up of SARS information. The former group in particular can be considered to have the most responsibility, as adherence to the ethical code relating to medical science should have prevented these professionals from obstructing the release of information.

Lesson from the SARS epidemic

Because of its extremely contagious nature and high fatality rate, the SARS epidemic has raised special medical and social ethical issues such as privacy, liberty and public health (1-5). Japan was relatively spared during the 2003 SARS pandemic, and serious ethical problems were therefore sporadic. In this sense, information control by the triad of medical experts, media and health officials was successful. Success in withholding SARS information might have led to these parties feeling vindicated, and even encouraged such a course of action; thus, similar information control might be repeated in Japan in the future under similar circumstances. However, the outcome was merely a matter of luck. In this era of information revolution, any attempt at information control may lead to the distribution of insufficient information, misleading data or rumors. Thus, from the viewpoint of crisis control and prevention, withholding information can exacerbate confusion and make the situation worse.

Problems derived from the triad of medico-aristocrats, media-aristocrats, and bureau-aristocrats are likely to take some time to resolve. Although change may be slow, open discussion with sound constructive criticism should be encouraged, with the aim of disrupting the tight connections of the triangle. In the meantime, it is hoped that medical experts, media reporters, and health officials will behave in accordance with their professional ethics.

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Table. Japanese definition of SARS and numbers of patients in each category

WHO definition*	Japanese definition	cumulative number of patients**
suspected case	utagai rei (suspected case)	52
probable case	kanosei rei (possible case)	16
-	kakutei rei (confirmed case)	0

* Briefly, a patient with symptoms was defined as a "suspected case" and a patient with symptoms + atypical pneumonia was defined as a "probable case." ** Figures from the Japanese Infectious Disease Surveillance Centre (6).