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OF EPIDEMICS

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ON TRUST AND HEALTH CONSENSUS-BUILDING IN THE GOVERNANCE OF EPIDEMICS

Stella R. Quah

In a free society organized along democratic principles, *governance* refers to the management of the affairs of the collective to ensure safety, fairness, and equality of opportunity for all its individual members. Social science and medical research indicate that epidemics test a society's governance effectiveness by endangering the lives of individuals, families, and entire communities (Whitman 2000, 6–10; Taylor 2002, 976–77; Blumenthal and Hsiao 2005; Patterson and London 2002 Haines et al. 2004; Fidler 2004a). HIV/AIDS and SARS are two of the major infectious disease epidemics we face today. The contrast between these two epidemics offers a singular lesson in public health governance for nations around the world. If the current avian influenza outbreak becomes a human epidemic, we will be preparing for a third major health crisis. It is timely, then, to learn as much as we can from the successes and failures in the governance of HIV/AIDS and SARS.

The governance of epidemics must be carefully scrutinized from both macro-(community) and micro-level (individual) perspectives. Examining micro-level data, I have discussed elsewhere (Quah 2007) how the individual's perception of disease severity and of his or her own susceptibility to the disease help to shape the public image of HIV/AIDS and SARS. These two elements in turn help to explain the differing prevention effectiveness of the two diseases. In this chapter, I follow a macro-level perspective to address another major factor in the governance of epidemics: the need to nurture public consensus or "collective informed consent" on the nature of the problem and the range of solutions available. I argue that the presence of collective informed consent is a crucial prerequisite for the successful governance of epidemics. Here, I propose and explore four major factors that influence the presence of collective informed consent. The first and most immediate factor is the level of the community's trust in the health authorities' expertise and integrity to solve health crises fairly and successfully. The level of trust, in turn, is influenced by three other factors: the transparency of state's actions and decision-making; the state's implementation of consensus-building by disseminating objective information on the nature of the problem, the available and recommended solutions, and incentives to facilitate preventive action; and the facilitation of community involvement in decision-making and crisis management.

These four factors must be present if the health authorities are to obtain collective informed consent and gain the corresponding cooperation from the community to address the epidemic promptly and effectively. These factors are dynamic and do not necessarily constitute a chain of events but, rather, a set of prerequisites to achieve collective informed consent. After considering the notion of collective informed consent, I discuss each of the four background factors separately and then explain their impact on the successful governance of epidemics.

Collective Informed Consent

In the world of clinical trials and biomedical care, the concept of informed consent as applied to individuals is essential and well understood. The human subject or patient must be respected as a rational, autonomous person who is entitled to make decisions and weigh the benefits and risks of alternative solutions to his or her health problem or to a health threat. Autonomy is a value that connotes “self-government and freedom of choice,” and consequently, “consent given by the patient is the only legitimate ground for almost any interference in their lives or any intrusion upon their person” (Engelhard 1986, cited in Harrington 2002, 1426). Following regulations agreed upon by the international community represented in the membership of the World Health Organization (WHO), informed consent must be implemented daily and routinely in biomedical interventions and clinical trials (USFDA 1998, USFDA 2006). According to informed consent guidelines, clear, complete, and unambiguous explanation of a given procedure—including its justification, benefits, and all known risks—must be given to the patient or human subject. Questions are encouraged and answered. Once the patient/subject is satisfied with the information, then he or she is invited to participate, and then must sign a consent form to proceed with the intervention or clinical trial, as the case may be.

In some instances, the clinical context of individual informed consent intersects with public health practice. For example, medical practitioners offer immunization and/or screening tests for an infectious disease, or bring these options to the attention of their patients. Prenatal HIV testing for pregnant women (Lo, Wolf, and Sengupta 2000) and routine HIV testing for other individuals also provide relevant illustrations of this intersection. Both situations tend to occur as practitioner-patient interactions in a private context, but it is widely acknowledged that patients’ private decisions have significant public consequences for the management of the HIV/AIDS epidemic (Baldwin 2005, 287; D’Amelio et al. 2001, 7–11; United Nations 1985). Unfortunately, the concept of informed consent remains anchored in the doctor-patient encounter. If informed public choices are mentioned in the realm of public health, their discussion regularly focuses on the needs of decision-makers (Haines et al. 2004). It is thus necessary to consider the scope of informed consent at the wider, community level.

What is collective or community informed consent? Community informed consent differs from individual informed consent in two ways. First, in community informed consent the subject is a collective entity: the community affected by the disease or disease threat. Let us understand community to mean the total population, involving persons affected by the disease (e.g., persons living with HIV/AIDS or SARS patients), their immediate families and networks, and the rest of the population residing in the same political jurisdiction (city, municipality, county, state, province, or nation state) and enjoying autonomy in health policy decisions. So defined, the community should be treated as a collectivity of rational and autonomous individuals, entitled to make decisions and weigh the benefits and risks of alternative solutions to their health problems or to a health threat. The same requirements of informed consent mentioned earlier apply: clear, complete, and unambiguous explanations of the nature of the problem or health threat should be distributed, including suggested solutions, their justification, their benefits, and all known risks; and questions should be encouraged and answered. Second, community informed consent differs from individual informed consent in the manner in which the consent is taken. With community informed consent, the process should include an assessment of the community's level of information on the problem and on what is needed to solve it, and the community's level of agreement or consensus on what is needed to implement the solution. Halperin and colleagues (2004) offer a good illustration of this process in their discussion of the distribution of information on all possible preventive measures against HIV/AIDS infection.

To deal successfully with an infectious disease epidemic, health authorities need an informed and committed community as an active partner. Health authorities cannot deal with a crisis without the community's cooperation, regardless of the expertise and number of health care personnel and the level of medical technology available. We know of severe difficulties that public health practitioners and lay community members have faced in battling disease outbreaks or epidemics (e.g., Singer 1994, Rollins 2004, Baldwin 2005, Barry 2004). The seriousness of the crisis is compounded when health authorities fail to mobilize the indispensable cooperation from a community of uninformed, indifferent, or at worst, misinformed and hostile individuals or groups. In other words, the most immediate factor influencing the successful governance of an epidemic is the presence of community informed consent. Because the containment and preventive measures vary in each epidemic and the socioeconomic, cultural, and political contexts are constantly changing, collective informed consent must be obtained for each public health crisis.

The Challenge of Building Trust

The history of epidemics around the world (e.g., Harrison 2004, Baldwin 2005) is rich with instances of reasons people have for trusting—or distrusting—the state in general, or government officials, or health authorities. Research findings

have stressed the importance of patients' trust for the successful management of the HIV/AIDS epidemic (Burris 2000; Valdiserri et al. 2000; Klosinski 2000; Lo, Wolf, and Sengupta 2000), but we need to analyze trust in the context of public health more specifically.

I propose that trust is a precondition to informed consent, and that in the context of public health, the level of trust the community places in the health authorities influences the likelihood of granting informed consent. Put differently, it is reasonable to assume that you would consent to undergo a medical procedure, intervention, or action provided that you understood the problem (threat or danger) and the solution intellectually and trusted the people who informed you and who would work on the solution.

The discussion of trust has occupied philosophers and social scientists for a long time. Summarizing the definitions provided by seven scholars from 1958 to 1993, Deborah Welch Larson concludes that trust is understood as "a judgment that one can rely on another party's word or promise at the risk of a bad outcome should the other cheat or renege" (2004, 35). In the context of family relations, trust may mean "the willingness to accept risk based upon stable, positive expectations of a partner's intentions" (Brown 2004, 168). On the other hand, trust in formal interactions among "anonymous actors" is defined as "the belief that other agents will act in a predictable way without special sanctions" (Radaev 2004, 233). More generally, trust is "placing valued outcomes at risk to others' malfeasance, mistakes, or failures" (Tilly 2005, 12). At an even higher level of abstraction, trust is found at both the socio-emotional and the rational spheres of social life. In the socio-emotional sphere, trust is embedded in the everyday life norms, roles, and expectations that hold a community together. That is, trust "may be regarded as an expectation that relevant others will behave according to certain norms that make their behavior dependable, predictable, or, as we say, trustworthy" (Wuthnow 2004, 146). The rational sphere of trust involves exchange interactions and the calculation of risk (however subjective). In other words, trust "is part of a rational actor's effort to calculate the cost and benefits of entering into a specified relationship with another person" (Wuthnow 2004, 148).

Both the socioemotional sphere and the rational sphere of trust are relevant in the analysis of what influences the presence of informed consent required to manage epidemics successfully. These two spheres point to the importance of the social context in which trust may exist or be impeded. Wuthnow (2004, 154) identifies ten reasons—or "warrants"—for why A may trust B:

- *Sincerity*, whereby "A is persuaded" of the sincerity of B
- *Empathy*, whereby A believes "B cares about A"
- *Affinity*, when "A senses that A and B have a shared identity, common values, or mutual understanding"
- *Altruism*, when "A expects B to exercise restraint over B's self-interest and to behave in a way that takes account of A's interests and needs"

- *Accessibility*, whereby “A anticipates that B will be available” when needed and “that A has a valid claim to B’s time and resources”
- *Effectiveness*, when “A regards B as efficacious, as able to get the job done or to achieve the desired results” and that B has the required “resources” and is able to mobilize them
- *Competence*, when “A perceives B as having appropriate training, information, skills, and talents for performing the role in question”
- *Congeniality*, whereby “A regards B as capable of engaging” in the task with ease, politeness, and friendliness
- *Fairness*, whereby “A expects B to follow prescribed procedures and abide by formal rules pertaining to B’s roles, thus treating A similarly to people who are in similar situations and not rendering arbitrary judgments”
- *Reliability*, whereby “A regards B as being dependable or stable by virtue of expecting B to behave in similar ways under similar circumstances over time.”

Applying Wuthnow’s trust “warrants” to the matter of epidemics, we may ask: Why should members of a community trust their health authorities? Research findings based on direct data (Quah and Lee 2004, Quah 2007) and indirect and historical data (Barry 2004, 448–61; Rollins 2004; Kleinman and Watson 2006; Lee and Yun 2006; Zhang 2006) suggest that of the ten warrants outlined by Wuthnow, nine are directly relevant to the presence of community consensus and cooperation (informed consent) in a public health crises. People in the target community tend to trust (or distrust) the government and/or health authorities based on their perception of the government’s sincerity, empathy, affinity, altruism, accessibility, effectiveness, competence, fairness, and reliability.

Citizens’ perceptions of these attributes on the part of the government (or government agencies, or officials) are shaped primarily by citizens’ inferences from their observations of and experience with government’s past behavior and actions (Hardin 2002, 153–56).¹ Sociological research demonstrates that trust is embedded in the community’s values and norms (Hardin 2004; Wuthnow 2004, Tilly 2005). But time is crucial. Psychological and sociological studies show that building trust is a slow process: the bricks of the trust edifice are the accumulated positive interactions among the individuals concerned over a period of time (Murnighan et al. 2004, 294). The level of trust may increase with time, “as each additional positive interaction becomes more valuable in establishing mutual trust” (2004, 294), but this general trend may not apply to intimate relations (2004, 320). The history of the interaction or relationship is also important, even as we acknowledge that “the trust development process is neither neat nor strictly rational” (Murnighan et al. 2004, 315; Taylor-Gooby and Zinn 2006, 399). Consequently, the community’s warrants for trust in their government and health authorities need to be nurtured and strengthened over

time—well before a health crisis strikes. The HIV/AIDS and SARS epidemics have brought to light this simple but important principle. Indeed, M. H. Merson's views on trust and the early detection of HIV infection underscore it:

There is a wide consensus that early detection of HIV infection to increase access to care and to decrease risky behavior in order to prevent infection is a laudable goal that should be vigorously pursued and researched. But enthusiasm for testing must always be tempered by the need for acceptance and trust of individuals and communities. This can only come through dialogue and partnership; it can never be legislated” (Merson 2000, S159).

In the case of SARS, the initial reaction to the outbreak, both among health authorities and the public, differed markedly from country to country: there are indications that governance effectiveness in controlling the outbreak differed across countries in tandem with a given country's governance style and a given community's level of trust in their health authorities (Zhao 2003, Quah and Lee 2004, Fidler 2004b, Chiu and Galbraith 2004, Kleinman and Lee 2006).

Building Warrants for Trust

The discussion of trust raises three factors that contribute to the building of warrants for trust: transparency in state's actions and decision-making, implementation of consensus-building mechanisms, and facilitation of the community's involvement in crisis resolution.

Transparency in State Actions and Decision-making

In a democratic system, it is expected that government actions and decisions will be accessible to the citizenry and open to scrutiny. Openness or transparency makes it easier for citizens to know how their government operates and why decisions are made, thus providing information that can nurture trust. Therefore, the building of warrants for trust depends, among other things, on transparency in the state's actions and decision-making. Transparency is important in normal times, but it becomes crucial in times of crisis. In the case of an infectious disease epidemic, distribution of information on the disease and rapid response are vital for the effective prevention and containment. With the current speed of transmission of infectious diseases such as HIV/AIDS and SARS, and the heavy toll that epidemics inflict on individuals and communities, timely and effective distribution of information on infectious disease outbreaks is needed to improve the global disease monitoring capabilities recommended by the United Nations (UN) (United Nations 2004, 29–31; Fidler 2004a, 801; Gostin 2004).

The need for transparency and, specifically, for global reporting guidelines is well understood and generally accepted by most UN member nations (Sim and Mackie 2006, Olowokure and Roth 2006, Shaw 2006). But the implementation of collaborative guidelines is less than ideal, even among modern industrialized

countries. The European community, for example, is still fine-tuning a system of collaboration in global case reporting, and there is hope that the European Centre for Communicable Diseases will provide the answer. Along the same line of thought, experts in England are studying the role played by the Health Protection Agency during the SARS outbreak (Goddard et al. 2006).

The slow pace of implementing transparency measures is problematic but not as serious as the problem of complete secrecy. Regrettably, historical and current events suggest that until the problem is verified, until a solution or way of controlling the danger is found, or until it becomes politically appropriate to reveal it, secrecy or concealment tends to be the most common impulse of officials who discover a potential danger. Indeed, concealing a threat or danger has been justified in many ways. For example, it has been cited as an effort to protect the community, to avoid panic, to keep the bad news from enemies or competitors, or to maintain for as long as possible the normal pace of work of those affected (Barry 2004, 169–75; Garrett 2005). In some countries, concealing disease outbreaks may be actually mandated. A vivid illustration of this problem is China's silence in 2002–03, during the crucial first months of the SARS epidemic.² One expert in international affairs writes that in Chinese law “epidemics fall under the classification of state secrets” and local officials “do not have the incentive” or “the power to make public comments about disease outbreaks before this has been announced by the authorities at the national level.” Not surprisingly, this situation “encourages optimistic reporting and the suppression of bad news.” In the case of SARS, this feature of Chinese governance caused “the delay in timely reporting and exacerbated the impact of the disease, causing precisely the kind of domestic and international crisis that the system is designed to prevent” (Saich 2006, 73).

In addition, at the micro-level, state secrecy confounds and interrupts the lives of individual members of the community facing a health crisis. State secrecy in a health crisis not only impedes a rapid and effective response to epidemics but also breeds, at best, misinformation, and at worst, panic among individuals and families. Without accurate information on what is happening and why, people activate their informal networks in whatever way possible—face-to-face, by telephone, through mobile phone text messages, and through email. People who can avoid or overcome panic resort to their traditional ways of thinking and of doing things, including traditional healing practices. During the SARS outbreak in Guangzhou, Hong Kong, and Taiwan, for example, rumors of disaster circulated, fast creating the panic-buying of traditional remedies like herbal medicines to increase body strength, and white vinegar. Residents believed that boiling white vinegar in a room would prevent the disease by killing germs (SARS Expert Committee 2003, 13; Kaufman 2006, 65). Unfortunately, families used charcoal stoves to boil pots of vinegar inside closed rooms, and this method led to cases of carbon monoxide poisoning (Abdullah et al. 2003, 1043). However, some traditional procedures people used in the absence of

other guidelines may turn out to be useful. The traditional Chinese belief in the sterilizing properties of white vinegar has been confirmed by scientific research: white vinegar has sterilizing properties not when it is boiled but when added to diluted household bleach (Miner et al. 2006).

The personal experience of one 23-year-old medical student as a SARS patient in Guangzhou, during the time of official concealment (Ho 2006), offers a compelling example of the danger, unnecessary anxiety, and suffering that state secrecy inflicts upon individuals. The medical student fell ill after treating a patient with severe pneumonia during a 20-minute ride in an ambulance on January 31, 2003. His own knowledge of medicine made him realize his symptoms were more serious than those of the common flu. The ambulance driver got sick the next day. Both the patient and the driver died some days later. For the first week of his illness the medical student dealt with his symptoms alone. At first he remained in his dormitory alone by choice. But when he sought medial attention later, the Emergency Room staff simply gave him “some acetaminophen and sent me back to the dorm.” Although the hospital had been dealing with at least two patients with “severe pneumonia,” when the student got sicker and returned to the ER, they gave him “some antibiotics and sent me home again. . . . I stayed in my bed for another two days with fever. I did not contact anyone and no one contacted me.” As the disease progressed the student was finally warded. He went through a very critical period and survived SARS. His perspective on the silence of the medical professionals with whom he worked and interacted is informative, since it suggests that the state’s preference for secrecy had spilled over into the health care system: “We all knew that the one [patient] transferred from a rural district north of Guangzhou had infected nine hospital staff before his transfer to our hospital, but we hardly talked about it.” There was also the plight of “nursing aids,” one of the lowest ranks of temporary workers who are hired by relatives to look after patients at the hospital “for a small fee.” The medical student observed that during the SARS outbreak nursing aids “were infected just like many doctors and nurses. They disappeared from the hospital site as soon as they got sick, for they could no longer work, nor could they afford the enormous medical fees.” M. S. Ho, the author who interviewed the student, noted that nursing aids who fell ill “would return to their hometowns and blend in with the 800 million farmers in the vast rural areas of China, carrying with them the SARS virus from Guangdong” (Ho 2006, 7). This is yet one more example of the tragedy of secrecy: when the state remains silent and abstains from urgently needed action, it leaves citizens to cope with the crisis on their own, and inflicts the most pain on the weakest, least educated, and poorest members of the community.

Consensus-building and Community Involvement

I indicated earlier that three factors are associated with the creation of warrants for trust: transparency in the state’s actions and decision-making, implementation of consensus-building mechanisms, and facilitation of the

community's involvement in crisis resolution. I turn now to the second and third factors.

The consensus-building mechanisms I discuss here are most likely to be devised in democratic systems of government, because these mechanisms presuppose respect for citizenry and a commitment to share rather than to conceal information. State authorities need to concern themselves with consensus-building to bring all the different sectors of the community together as partners in the collective endeavor of conquering a common problem or threat, whether it is poverty, crime, addiction, or an infectious disease epidemic, or other shared problem. For public health, three consensus-building mechanisms are necessary. First is the distribution of objective—that is, empirically verifiable—information on the problem and on its nature, etiology, diagnosis, and prognosis. Second is the distribution of objective—again, empirically verifiable—information on the range of available solutions, and on the known benefits and risks of the recommended solutions. The key feature of these two types of information is that they *must* be empirically verifiable, which makes them the exact opposite of propaganda. Propaganda is the exercise in “mass suggestion or influence through . . . the dexterous use of images, slogans and symbols that play on our prejudices and emotions” (Pratkanis and Aronson 2001, 11). History shows that opportunistic politicians and interest groups do not hesitate to use propaganda to take advantage of people's vulnerability during a health crisis (Barry 2004, Baldwin 2005). In contrast, in the battle against an epidemic, the goal is to educate the population on all known relevant aspects of the problem at hand, all possible solutions available, and the current limits of that knowledge.

These two first steps toward consensus-building provide the community with complete and useful information on the problem and on what the community can do, collectively and individually, to solve the problem. As discussed earlier, information sharing in a transparent and verifiable manner is conducive to creating and strengthening trust.

However, research findings indicate that information on a disease threat and possible preventive action does not necessarily lead the target population to put into practice the recommended actions. In other words, information alone is insufficient to motivate preventive behavior (Gochman 1997; Quah 1985, 1988; Quah and Lee 2004). Thus, a third step is necessary: to identify and introduce incentives to practice preventive action. This third consensus-building mechanism is indispensable, because in the prevention of infectious disease epidemics it is crucial to ensure that all members of the affected community follow the recommended preventive actions. Like all infectious disease epidemics, SARS showed us clearly that one individual's actions may be enough to spread the disease to unsuspecting communities.

When the problem or crisis is sufficiently serious—to the point of threatening life and limb—the desire for safety becomes the built-in incentive to follow a recommended course of action that is believed to be effective. This desire for safety works as an incentive if two of the warrants for trust (Wuthnow

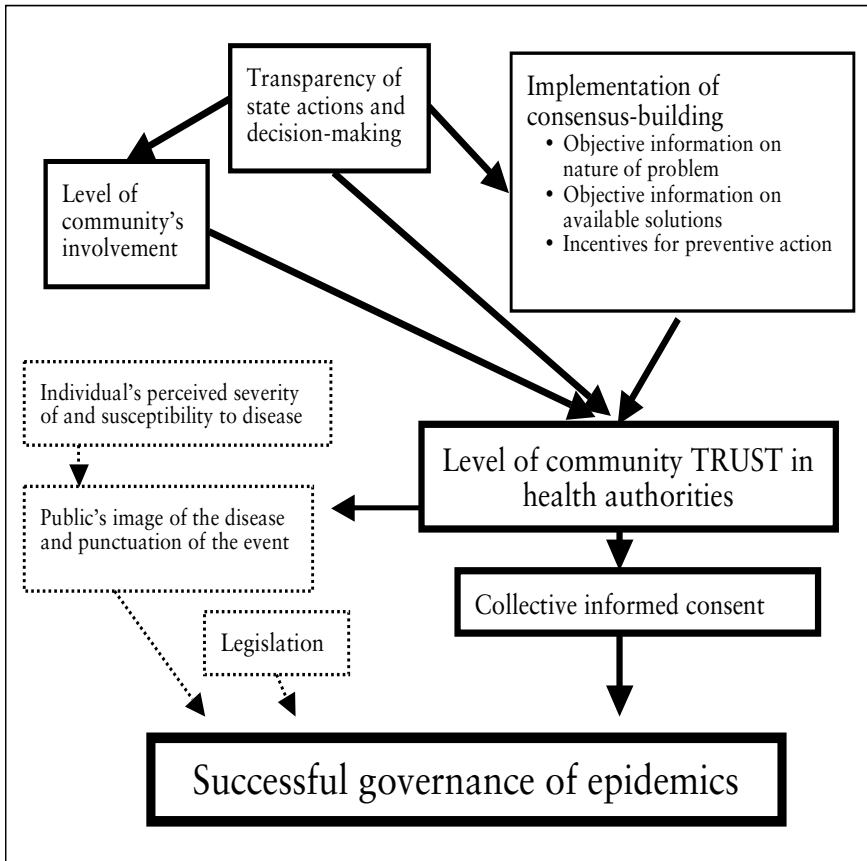
2004) are present: effectiveness and competence. Effectiveness occurs when the community regards health authorities as capable of getting the job done or achieving the desired results, and believes that the government has the required resources to deal with the crisis and is able to mobilize them. Competence applies when the community perceives the health authorities as having appropriate training, information, skills, and talents to control the crisis and protect the population.

To facilitate the community's cooperation and involvement, the state must not only share information but also create diverse channels of communication. But effective communication must be a two-way system, rather than a top-down transmission of directives. Community feedback and queries from individuals, groups, associations and other sectors of civil society are crucial elements in the health authorities' search for solutions to the crisis and in its effective implementation of those solutions.

Toward Successful Governance of Epidemics

Legislation is an integral part of the traditional management of epidemics, both in the national and international arenas (Gostin 2004; Patterson and London 2002, Taylor 2002, Whitman 2000, James et al. 2006, Quah and Lee 2004). In this discussion, however, I take legislation as a given and focus instead on this wider principle: The *sine qua non* of successful crisis governance is the groundwork that is laid before the crisis. This principle has been recognized in various fields. In his assessment of leadership moments in organizations, management expert Michael Useem (1998) explains that the required groundwork includes “a strong culture with good lines of interior communication, mutual understanding, and shared obligation,” all of which “are essential ingredients to ensure that your team, your organization, or your company will perform to its utmost when it is most needed” (1998, 64). Sociologist Amitai Etzioni (1993) stresses the same point with respect to government and the citizenry in nation states. My research indicates that the same requirement applies to the successful management of health crises (for example, infectious disease epidemics) by the state and its citizens. I propose in this chapter that community involvement, transparency, consensus-building, and efforts at strengthening trust constitute the groundwork needed to create prompt and effective responses to a crisis (see Figure 1). These features take time to build. Crises are likely to cause more harm and take longer to resolve in countries where the spectrum of factors needed for successful governance (collective informed consent, transparency, procedures for consensus-building mechanisms, and the warrants for trust) is weak or not present when the crisis strikes.

Figure 6.1. Main Factors Influencing the Governance of Epidemics



Note: The solid-line boxes indicate the factors discussed in this chapter. Factors in the dotted-line boxes are discussed elsewhere (Quah 2007).

The governance of SARS in some Asian countries illustrates the importance of preliminary groundwork. For example, community involvement and the three consensus-building mechanisms were already present in Singapore before SARS struck (Quah and Lee 2004). Whatever medical experts knew at the outset about the disease's etiology, diagnosis, and prognosis was passed to the population through all mass media channels. New channels were created to reach more people, including a dedicated television channel, several public websites, and other website pages that many organizations set up to provide SARS prevention guidelines to their members and employees. Technical and scientific information

on the SARS coronavirus were publicized in various ways—from cartoons to pamphlets and from TV to radio programs—to facilitate understanding among people from all walks of life. Basic preventive actions that every person was to follow during the outbreak included taking and recording one's body temperature twice a day with one's personal thermometer;³ washing hands thoroughly as often as necessary; modifying the daily practice of sharing meals by using separate serving utensils even when eating at home with one's family members (a traditional Asian practice is to serve dishes in common plates or large bowls from which each person around the table partakes); and strictly limiting outside-home activities (Quah and Lee 2004, Chua 2004, James et al. 2006). Those preventive actions impinged upon everyone's daily life but the major incentive of following the recommended precautions was that those precautions were effective in preventing the spread of the disease.

It should be noted that at the start of the epidemic there was considerable uncertainty in medical circles about the nature of the infection and how to prevent it. This situation was conveyed to the population and information was updated continuously as more knowledge about the disease was acquired. Meanwhile, scientific research was accelerated, through active networking on both the international and the local levels. One outcome of local research was the cooperation between the Defense Science and Technology Agency and Singapore Technologies Engineering to develop thermal imaging scanners, which were installed at all Singapore's ports of entry to detect fever among passengers leaving and arriving. The scanners became "hot items sought by Asian governments battling SARS," including Hong Kong, the Philippines, China, Taiwan, and Thailand (Deutsche Press-Agentur 2003).

Battling the SARS outbreak in Singapore was an exercise in collective learning, but the goal of collective action was safety: to control and stop the disease outbreak. This goal served as the best incentive for the community to follow the recommended preventive actions. Subsequently, as added incentives, arrangements were put in place to minimize the financial cost of quarantine and other preventive measures for individuals and organizations (James et al. 2006).

Many countries affected by the SARS outbreak could not respond in the same systematic manner. Within the health care system, hospitals were at the forefront of the epidemic, but as a study of hospitals in Laos, Taiwan, and Thailand reveals, there was discordance between the hospital epidemic control guidelines and the implementation of those guidelines (Lee et al. 2004). Requests for preventive action by health authorities in several countries were originally greeted with noncooperation (Foreman 2003). China's extremely inadequate governance of epidemics such as HIV/AIDS and SARS is well documented (Saich 2006, Ho 2006, Baldwin 2005).

Other countries, too, have faltered. In the absence of the governance groundwork just discussed, Taiwan faced serious setbacks while trying to manage the SARS outbreak at the beginning of the epidemic. One of the major

management problems was the reluctance of the Taiwanese population, and even health care personnel, to follow the health authorities' recommendations, particularly concerning quarantine. The first SARS case in Taiwan was diagnosed "in early March 2003" (Deng et al. 2006, 16). On April 21, 2003, Taipei's health authorities declared the Hoping Hospital in quarantine for two weeks, as the hospital had ten probable SARS cases and some staff members had been infected. The public health experts had determined correctly that quarantine was the safest course of action. Even so, some 30 nurses and other health care workers protested raucously. Some tossed "bottles and paper out of windows and displayed banners saying "Wrong Policy" and "Long, Long 14 days" (Foreman 2003, Wu 2003). Explaining to a reporter why people did not follow quarantine regulations, one Taiwanese public health expert said, "Taiwan is too democratic to execute quarantine with an iron fist like Singapore. But, more importantly, quarantining is disruptive of people's lives. The government needs . . . to find a way to accommodate their needs" (Shu 2003). His comments reveal the absence of the necessary groundwork to face the epidemic, particularly the lack of accurate information on the nature of the disease, the low level of trust that the community placed in their health authorities, and consequently, the absence of collective informed consent.

By its very nature, informed consent cannot be forced upon a community. Baldwin explains this point well in his historical analysis of disease and democracy: "Modern democratic societies could not control citizens' behavior through prescribing conduct. . . . Instead, they sought to rear, educate and persuade inhabitants to act as members of a civilized polity" (2005, 263). As the SARS epidemic developed and spread to other countries, a process of learning by doing began to take place.

Conclusion

I have argued in this chapter that without the crucial factors of effective channels for community participation in decision-making, transparency, effective democratic mechanisms of consensus-building, warrants for citizens' trust in the health authorities, and collective informed consent, the prospect of successful governance of health crises remains uncertain.

Hopefully, today we are wiser from the SARS experience, but future epidemics may find some countries still unprepared. The governance of epidemics is a serious concern because in the realm of infectious disease epidemics, we live in a borderless world. A vivid reminder of this is the avian influenza threat, which comes from the organized smuggling of poultry (either live birds or raw meat) across Asia and Europe (Rosenthal 2006) and very likely in other world regions. In addition to natural bird migration, illegal trade fuels the spread of the A(H5N1) virus that causes avian influenza, and must be counteracted with "tough" legislation (Bradsher 2006). But human air travel is potentially a more rapid mode for transmitting the virus (compared to the usual "natural" spread

through bird migration), and requires the urgent attention and cooperation of governments everywhere (Lim 2006; Omi 2006, viii).

Some of the actions taking place in countries currently battling the avian influenza outbreak among fowl give cause for optimism. One of the actions, for example, is to provide public announcements on what authorities are doing about the disease (Chou 2005), such as setting up emergency surveillance arrangements. Such regular publicity keeps the topic in the media and ensures that people remain alert to the problem. Nevertheless, as one experienced epidemiologist declared, surveillance systems “can be set up very quickly” but “this is not a mode of operation we should come to depend on” (Foegen 2000, 214).

There are also indications that the groundwork for successful governance of future epidemics has not begun in some countries and that very few have learned from the SARS outbreak. International experts express concern about China’s level of preparedness for a new epidemic, because of its inadequate monitoring mechanisms for infectious diseases at the county and village levels (Blumenthal and Hsiao 2005, 1169); its persistent tendency toward secrecy (Agence France-Presse 2005, Osnos 2005, McCord 2005); and the danger of corruption in handling a massive inoculation of poultry in the country (Bezlova 2005). The manner in which the culling of birds and poultry is being planned and implemented to avoid an Avian flu epidemic also indicates that the lessons from SARS on the importance of collective informed consent have not been learned. The task is multiple and challenging: to reach farmers (usually poorly educated) in remote rural areas, to communicate to them the seriousness of the disease and the necessity of bird culling—which typically terminates their main source of income—and to provide real incentives for their cooperation. However, in many affected countries, including Iran, Turkey, Romania, Ukraine, Moldova, and Nigeria, the health authorities apparently have concentrated their energies on the logistics of bird slaughtering (transport of slaughtering equipment, personnel, paraphernalia, and the like) but have neglected or paid less attention to informing the farmers of the etiology, diagnosis, and prognosis of the epidemic affecting their flocks and, particularly, to explaining the nature, justification, and effectiveness of culling as preventive action. Not surprisingly, farmers have protested and failed to cooperate. Some have even tried to salvage their source of livelihood by hiding their ducks and chickens from inspectors (Farmani 2006, Cheviron 2006, Ingham 2006, *Rompress* 2005, Chiriac 2005, Akhaine et al. 2006). The affected farmers are naturally anxious and wary of health inspectors, unwilling to trust government officials from faraway cities. In the farmers’ eyes, most officials know nothing about farming and do not care what happens to farmers.

Finally, then, in addition to the factors needed to create informed consent, the governance of a health crisis or epidemic must include effective international and national coordination. The international or global governance of infectious diseases has received considerable attention (Fidler 2004a and 2004b, Whitman

2000, Taylor 2002, Gostin 2004). Equally important are national governments' arrangements to adapt internal procedures and personnel and to shift their civil service and health care systems into a crisis management mode. Such internal arrangements will vary across countries, given differences in political system, political ideology, geographical constraints, and socioeconomic context.

Still, irrespective of these differences, three arrangements are likely to bear fruit in most countries. The first is the active coordination of ministries and other state agencies to share information, to deal with the problem in a synchronized fashion, and to respond to the crisis promptly and consistently. The second is to design a multi-pronged approach to the solution of the health crisis. No single solution is likely to be sufficient in combating an epidemic. A multi-pronged approach means rallying significant sectors of society to cooperate—including, among others, scientists, professionals, security experts, university students, schools, the armed forces, religious groups, retired people, businesses, and nongovernmental organizations. This collaborative effort may be formalized by establishing one or more task forces entrusted with specific responsibilities. The third arrangement begins by using existing legislation. Then, because each crisis or epidemic brings its own demands, health authorities must be prepared to introduce specifically designed regulations to deal with each crisis within the framework of collective informed consent. These three additional arrangements require, of course, constant fine-tuning, in light of advances in technological and scientific knowledge, the nature of the disease, and changes in the demographic, socioeconomic, and cultural features of a given population.

Notes

1. Some readers may like to know that Russell Hardin (2002, 155–56) labels this citizens-government situation “quasi trust.” In Hardin’s opinion, quasi trust differs from individual-to-individual trust relations, in which each individual has some knowledge of the other that helps him or her to estimate the other’s trustworthiness. Hardin suggests that quasi trust occurs in all situations involving institutions and other collective entities because “it is grounded in inductive extrapolation from past behavior or reputation” (2002, 156). Hardin correctly points to extrapolations, but it is commonly recognized in the literature that such an extrapolation is present in most situations involving trust. I therefore continue to use the term “trust” in this discussion.

2. The first SARS cases were seen in Foshan, a city in the southern Chinese province of Guangzhou, in November 2002. Clinicians originally mistook these cases as possible avian flu but later labeled them “atypical pneumonia.” However, no reports or surveillance followed because “pneumonia, atypical or otherwise” is not on China’s list of communicable infectious diseases. As a result, the outbreak “was kept from the public in Guangdong until February 11,” when the epidemic was reported to the World Health Organization (WHO) after the Guangdong Provincial Health Bureau “initiated an inquiry based upon reports received from Hong Kong’s Global Outbreak Alert and Response

Network (GOARN),” a network set up by WHO” after September 11, 2001 (Kaufman 2006, 53–68).

3. The Singapore government distributed free thermometers to all educational institutions’ students and teachers, as well as to the armed forces, civil service, to any other organizations that requested them, and to individuals through clinics and hospitals and other health care institutions (Chua 2004, James et al. 2006).

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