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Ethical Issues in SARS Control

Diploma Thesis

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> The only freedom which deserves its name, is that of pursuing
> our own good in our own way, so long as we do not attempt
> to deprive others of theirs, or impede their efforts to obtain it.
> The only purpose for which power can be rightfully exercised
> over any members of a civilised community against his will, is
> to prevent harm to others.
>
> *John Stuart Mill; 1806-73*

This work is dedicated to Dr. Carlo Urbani, a World Health Organisation expert on communicable diseases. Dr. Urbani first identified an atypical pneumonia and named it severe acute respiratory syndrome (SARS). On 29 March 2003, less than 4 weeks after responding to the first case of SARS, Dr. Urbani died of the disease. And his dedication was not unique. I would like to pay my tribute to health care workers all over the world at the front lines during the SARS epidemic.

Summary

In November 2002, severe acute respiratory syndrome (SARS) emerged in China and spread rapidly around the globe. The pathogen was unknown, and no vaccine or effective therapy was available. The initial steps taken to cope with SARS on the international, national and local level were made in uncertainty and without scientific knowledge. SARS is a reminder of the infectious diseases which continually threaten the public. The society reacted with fear and panic. Besides social disruption and economic losses, political response to infectious diseases posed ethical conflicts. The central conflict was protection of the public good versus protection of individual rights. SARS was already contained, the ethical issues persisted.

This diploma thesis provides an insight into this topic. The thesis is divided into two sections. The first section provides background information and the second is the manuscript of an article. The subject of the background information is infectious diseases; the relationships among ethics, public health and politics; professional codes of ethics provided for health care workers (HCWs), information on the evolution of public health ethics, and the development of the SARS epidemic in association with ethical conflicts.

The article describes a systematic literature review that was conducted to identify and discuss ‘ethical issues in SARS control’. It provides an insight into how people behave in emergencies, how SARS affected the health of the public and HCWs, and how politics responded to the crisis with implications for an effective infectious disease control. From 46 articles retrieved by PubMed, using ‘SARS and ethics’ as search terms from 11/2002 to 3/2006, 30 articles met the including criteria. The eleven identified ethical issues were categorized into three main groups: (1) Clinical ethics; (2) Public health ethics; and (3) Global health ethics. These ethical issues were discussed with respect to different political systems. Recommendations can support decision-makers in developing appropriate and effective strategies against SARS and SARS-like diseases with pandemic potential to ensure that infectious disease control is not only a method for preventing and treating infectious diseases but also a means of supporting public health.

Zusammenfassung

Im November 2002 kam es zur Ausbreitung des Schweren Akuten Respiratorischen Syndroms (SARS). Der Erreger war unbekannt und weder eine Impfung noch eine geeignete Therapie waren verfügbar. Die SARS Epidemie demonstrierte die zunehmende Bedeutung von neu auftretenden Infektionskrankheiten für den Public Health Bereich. Die Kontrollmaßnahmen zur Bekämpfung der Epidemie wurden ohne wissenschaftliche Kenntnisse umgesetzt. Die Reaktionen der Bevölkerung gingen mit Angst und Panik einher. Neben sozialer Unruhen und erheblichen wirtschaftlichen Verlusten, waren ethische Konflikte die Konsequenz der Infektionskontrolle. Der zentrale Konflikt beschreibt den Schutz des Allgemeinwohls versus den Schutz der Individualrechte. Obwohl SARS nach kurzer Zeit erfolgreich eingedämmt wurde, bestehen ethische Konflikte in der Infektionskontrolle fort.

Einen Überblick über diese Thematik soll diese Diplomarbeit geben, welche in zwei Teile gegliedert ist. Der erste Teil beinhaltet Hintergrundinformationen, der zweite Teil stellt das Manuskript einer Publikation dar. Die Hintergrundinformationen beinhalten Themen zu Infektionskrankheiten; die Beziehung zwischen Ethik, Public Health und Politik; Ethische Kodes für Angehörige der Heil- und Pflegeberufe; Informationen zur Evolution einer Ethik für Public Health als auch unterschiedliche Positionen dazu; sowie die Darstellung der SARS Epidemie assoziiert mit ethischen Konflikten.

Der Artikel beschreibt einen Literatur Review, in dem ethische Aspekte der SARS Kontrolle identifiziert und diskutiert werden. Es wird ein Einblick gegeben, wie Menschen sich in Notfallsituationen verhalten, wie SARS die Öffentliche Gesundheit und die der Angehörigen der Heil- und Pflegeberufe beeinflusste und mit welchen Kontrollmechanismen die Politik auf die Krise antwortete. Von 46 Publikationen, die in PubMed unter ‚SARS und Ethik' von 11/2002 bis 03/2003 verfügbar waren, entsprachen 30 Publikationen den Kriterien der Relevanz. Insgesamt wurden elf ethische Konflikte identifiziert und drei Kategorien zugeordnet: (1) Clinical ethics; (2) Public health ethics; und (3) Global health ethics. Die ethischen Konflikte wurden in Bezug zu unterschiedlichen politischen Systemen diskutiert. Handlungsempfehlungen können für die Entwicklung von effektiven Strategien zur Infektionskontrolle von SARS und ähnlichen Infektionskrankheiten mit pandemischem Potential eine Unterstützung für politische Entscheidungsträger darstellen.

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List of Abbreviations

AIDS	Acquired Immuno-deficiency syndrome
AMA	American Medical Association
ANA	American Nurses Association
CDC	Centers for Disease Control and Prevention
ECDC	European Centre for Prevention and Disease Control
HCW	Health care worker
HIV	Human Immuno-deficiency-virus
HKSAR	Hong Kong Special Administrative Region
ICCPR	International Covenant on Civil and Political Rights
ICESCR	International Covenant on Economic, Social and Cultural Rights
ICN	International Council of Nurses
IHR	International Health Regulations
ISC	International Sanitary Conference
ISR	International Sanitary Regulations
PPE	Personal protective equipment
SARS	Severe acute respiratory syndrome
TRIPS	Trade-Related Aspects of Intellectual Property Rights
WHO	World Health Organization
WMA	World Medical Association
WTO	World Trade Organization

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1 Infectious Diseases in a Globalized World

1.1 A View from the Past to the Future

The Past

History repeats itself. In the 19th century, the plague occurred in China without any evidence of a causative agent, and soon spread to Hong Kong. It was carried by ships to California and further on to South America, Africa and Asia [Yuen et al. 2005, pp. 1-10].

Similarly, it happened with severe acute respiratory syndrome (SARS) in late 2002. It emerged in Guangdong Province, South China, spread to Hong Kong, and then travelled international air routes and affected 29 countries all over the world [Heymann 2004].

Historic literature tells us that the plague wiped out one third of the European population in the 14th century. There were three human influenza pandemics in the 20th century, including the Spanish influenza in 1918 which took about 20 million victims, double the number that were killed during World War I. According to the World Health Organization (WHO), infectious diseases are at present the leading cause of death worldwide [Selgelid 2005].

Globalization

The term ‘Globalization’ refers to the increasing international integration of markets for services, goods, capital, knowledge and labour. Today, the rapid changes in electronic communication, new information technologies and transportation, have generalized the expansion of global economic activity which includes increased international trade, travel, tourism, and migration. Globalization has changed the life of many people, in every region of the world, in developed as well as developing countries. It presents new challenges as diseases spread rapidly from one country to another, around the world.

In the Middle Ages it took three years for the plague to spread from Asia to Europe. The SARS virus crossed from Hong Kong to Toronto in 15 hours [Singer et al. 2003].

The numbers of international airline passengers are additional proof of an interconnected world. From two million a year in 1950, the number has risen to about 1.4 billion [WHO 1999]. SARS had an enormous economic impact, estimated to be as much as high as US$100 billion [Tzeng 2004], and caused social disruption far beyond the countries affected due to the insecurity of dealing with an unknown disease.

In the 1980s, it took two years to identify ‘Human Immuno-deficiency-virus’ (HIV) as the cause of ‘Acquired Immuno-deficiency syndrome’ (AIDS). In 2003, the WHO created an extraordinary global network in ten countries, which identified a virus associated with SARS in two weeks and had its entire genome sequenced in two weeks more [Bloom 2003].

The Future

In each of the past 30 years, a new infectious disease has been identified [Brower 2003]. Examples include the Ebola virus in 1977, Legionnaire’s disease in 1977, HIV/AIDS in 1981 and in 1997 H5N1 influenza A or avian flu. The West Nile virus is an example of increasing geographical spread. First discovered in Uganda in 1937, in 1999 it occurred in the USA, and in the past decade outbreaks have increased in Europe and the Middle East. Tuberculosis is an example of a re-emerged infectious disease which had been a public health problem, only for vulnerable populations in developing countries, but now again has emerged in developed countries with the occurrence of drug resistant tuberculosis bacteria [Krämer A and Reintjes R 2003, pp. 15-22; National Advisory Committee Canada 2003].

For a new infectious disease to emerge, three conditions have to be met. It requires a new virus subtype, introduction into the human population with ensuing serious illness, and the ability to spread easily among humans. The containing of zoonoses therefore was one lesson to be learned from SARS, because they are mainly responsible for emerging infectious diseases. SARS *corona virus* is believed to be an animal virus that crossed the species barrier to humans. This can happen when ecological changes or changes in human behaviour increases the possibility for human exposure to the virus and virus adaptation may allow a human-to-human-transmission [WHO 2005a]. SARS was probably transmitted from wild game markets in Guangdong, China. Even though SARS was not behaving like the next great pandemic, experts expect within the next decade a new influenza pandemic [Singer et al. 2003], which would probably have a much worse effect on economies and societies than SARS has so far demonstrated.

In spring in 2006, the influenza A (H5N1) was a hot topic. Normally the H5N1 viruses circulate among wild birds and poultry. Only rarely have they infected humans [CDC 2006]. A combination of genes between human and avian strains was the likely cause of the Asian influenza (H2N2) in 1957 and the Hong Kong influenza (H3N2) in 1968 [Klempner et al 2004].

Since 1996, the virus H5N1 has caused epidemics in birds in many Asian countries with a high mortality. In 1997, people in Hong Kong became infected. Some died. The current epidemics started in South-East Asia in 2003 and spread in 2004 to Eastern, and in 2005, to Western Europe. Most of the affected countries had had no experience with epidemics of the highly contagious H5N1 pathogen [WHO 2005a]. Although the European Union has not been heavily affected by SARS, nobody can guarantee that the next epidemic will not emerge in Europe.

The best way to prevent an influenza pandemic would be the elimination of the virus from birds, but this is unlikely to succeed. Therefore the management of infectious diseases requires extraordinary efforts, even though the public health response for the first epidemic in the 21st century was apparently successful. More effective strategies of the political response on every level, from global to local, are essential for society to be better prepared for the next epidemic with its diverse health care systems as well as different cultures and socio-political traditions. This response to infectious diseases will be described in the following part of this section.

1.2 The Political Response to Infectious Diseases

The world is changing and only some public health risks stay within national borders. New agents have emerged and old known diseases have re-emerged, coupled with increased global traffic, trade, tourism, and migration. Most infectious diseases are preventable and treatable. SARS was not, nor will a new influenza pandemic be. In some ways SARS was a wake up call. It showed the necessity of assisting public health work in preventing and controlling the spread of infectious diseases by rules, regulations and laws.

The link between international law and infectious diseases is rooted in 1851, when the first International Sanitary Conference was convened by France. The need for multilateral cooperation in the field of public health with the evolution of the International Sanitary Regulations (ISR) came to the fore due to cholera epidemics in 1830 and 1847 in Europe.

The ISR was one of the oldest international political instruments to provide a set of rules to protect the global world from the spread of ‘quarantinable’ diseases [Pang and Guindon 2004]. In 1951, these regulations were adopted by WHO and were re-named in 1969, the International Health Regulations (IHR) [WHO 2002]. These regulations provide a legal framework for global surveillance and measures for containing the global spread of infectious diseases [WHO 2003a]. The IHR are binding for all 192 WHO member states. They were designed to “ensure the maximum security against the international spread of diseases with a minimum interference with world traffic” [WHO 2002, WHO 2005b]. To ensure maximum security against the global spread of a disease, a global surveillance system was established for diseases that are subject to the IHR. This requires, at ports and airports, special types of health related capabilities such as screening and travel advisories. To ensure minimum interference with global travel and trade, the IHR set out the most restrictive health measures, member states of WHO may take to protect its territories against an infectious disease subject to the IHR [Fidler 2003]. These regulations were used during the SARS epidemic to issue travel advisories for SARS affected areas to contain the spread of disease. Until recently the IHR were restricted to three diseases: cholera, the plague and yellow fever. Newly-emerged infectious diseases such as HIV/AIDS, or more recently, SARS, were not included and nowadays, trade and travel have expanded far beyond what was required under the original regulations. This led to a revision of the regulations in 2005 with the guiding principle of preventing an international spread of disease that could pose a risk to global public health, by early detection of, and effective response to such events [WHO 2005c].

Because cooperation is essential not only on a global level but also between national institutions, the European Centre for Disease Prevention and Control (ECDC) was started in 2005. The ECDC has guideline character binding on all parties while respecting subsidiarity principle. The responsibility for outbreak investigation and control in most of the EU Member States lies at the local or regional level [ECDC 2006].

On both the national and federal level, most western countries have statutory laws for infectious diseases where the measures that need to be taken in case of a health threat like SARS are constituted. Most national governments have public health statutes under which isolation and quarantine, as control measures for infectious diseases, are authorized, even if many of these statutes are old and have not been used for years.

According to Gostin et al. [2004], the quarantine statute in Virginia/USA was limited to only one sentence and the isolation statute only to tuberculosis and HIV/AIDS, which would not work in the case of SARS or other rapidly spreading infectious diseases, why revision of these inadequate infectious disease laws was required. Gravely [Gostin et al. 2004] pointed out how important the task of updating infectious disease laws is, and to identify and understand issues such as the imposition of mandatory quarantine, the use of private facilities and the role of media.

Public health belongs to one of the few professions which have legal power. Law can be used to coerce citizens into behaving in a healthy way. One example is the enforcement of immunization or quarantine and isolation to contain the spread of an infectious disease. There is a long relationship between ethics and law. Most public health laws and regulations imply an explicitly moral purpose, namely the protection and promotion of the lives of citizens. According to Jonathan Mann [Childress et al. 2002], public health officials should have two fundamental responsibilities: protecting and promoting public health and protecting and promoting human rights, which are linked to general moral considerations. In some situations, a society cannot realize both its commitment to public health and to human rights such as liberty, privacy, or confidentiality of individuals.

The tension between governmental obligation to public good and individual rights demonstrates the central conflict evolved in the SARS epidemic [Callahan and Jennings 2002]. SARS has furthermore illustrated the dependence of infectious disease control measures on various political systems. In democratic systems these measures were mostly voluntarily applied, in one-party states, mostly enforced. To maintain the health of the population, legislation that subordinates some individual rights is necessary [Kian and Lateef 2003]. How to strike a balance between the public’s health and individual rights? The next chapter provides an approach to this question.

2 Ethics, Public Health and Politics: A Strong Relationship

2.1 Ethics: What, Why, and Why Now?

Ethics is a main element of philosophy and is *'the reflection of moral values'* [Wehkamp 2006]. Morals can be understood as the common denominator of the ethics of various groups in society. Morals are common rules accepted in society as to how people should behave. Ethics depend on cultural and timely changes in societies. Because ethics are socially constructed, reflection on them is, from time to time necessary in order to be aware of the changing values in societies. Consequently, solving ethical problems needs an understanding of the context as well as of all people involved.

Ethics is not simply 'doing the right thing' or 'feeling the right way', but rather, ethics tries to converge to what the 'right' thing to do is [Loewy 1989, pp. 96-9]. It can not provide all the answers, but ethical considerations are helpful for clarifying decisions and for guiding our thinking. An ethical dilemma appears when there are two or even more competing interests at play. Responsible decisions are not easily made. In the case of infectious diseases the central dilemma is the protection of public health or the 'common good' versus protection of individual rights. For decision-makers in public health it is not clear how to judge when decisions have far-reaching consequences for society and economics – in particularly when no scientific knowledge about a disease such as SARS is at hand. According to Donnan [2003] the 'right' thing to do in public health practice has mostly an ethical, as well as a scientific dimension.

To answer the question 'What is the 'right' thing to do?' another question has to be taken into consideration 'How does one get people to do the right thing?' [Hinderer et al. 2001, pp. 17-8]. In cases of epidemics it is important to communicate public health interventions in a transparent way which engenders trust and compliance in society. This helps to contain the spread of the disease. According to Wehkamp [2006] *'ethics is the art of decision-making'*.

The next chapter concerns what means of guidance professional codes of ethics provide regarding the duty of health care workers (HCWs) to care. The emergence of SARS demonstrated that HCWs will henceforth be an integral part of any response to an epidemic and provide an opportunity for a review of professionalism among HCWs.

2.2 Professionalism and Duty to Care

In this work the abbreviation 'HCW' includes all professional care deliverers involved in a pandemic response.

Code of Ethics for Physicians

A physician's obligation to treat patients during epidemics, even at personal risk, emerged in the Hippocratic era. When infectious diseases became a recognized threat, the documented reaction in the face of the risk diverged. Many physicians continued caring for their patients, but many refused their care and fled from the cities following the advise they gave to patients – *cito, longe, tarde*: 'leave fast, go far, and return slowly' [Huber and Wynia 2004]. Reports of Ebola epidemics in Central Africa give an account of HCWs who fled their posts from fear of contracting Ebola or on the advice of family members [Hewlett and Hewlett 2005].

The duty of physicians to treat in epidemics was first established in the Code of Medical Ethics by the American Medical Association (AMA) in 1847 and adheres to following provision:

> *'…when pestilence prevails, it is (physicians') duty to face the danger, and to continue their labours for the allevation of suffering, even at the jeopardy of their own lives' [Huber and Wynia 2004].*

This Code was organized according to relationships between the physician and patient; and the physician and physician. The third relation between physician and the public was a new obligation first mentioned by the AMA.

According to the Working Group Three [2006], most codes of ethics do not provide the level of risk that HCWs should take while caring for patients. A review of published codes of ethics by this Working Group found out that only few codes explicitly mentioned infectious diseases emergency. The AMA adopted a policy document in 2004 'Physician Obligation in Disaster Preparedness and Response':

> *'National, regional and local responses to epidemics […] require extensive involvement to physicians. Because of their commitment to care for the sick and injured, individual physicians have an obligation to provide urgent medical care during disasters. This ethical obligation holds even in the face of greater than usual risks to their own safety, health of life.*

> *The physician workforce […] is not an unlimited resource; therefore, when participating in disaster responses, physicians should balance immediate benefits to individual patients with ability to care for patients in the future' [AMA 2004].*

These provisions do not consider the assessment of the level of risk to be taken by physicians [Working Group Three 2006].

The World Medical Association (WMA) recommends in their 'Statement on Medical Ethics in the Event of Disasters' revised in 2006, disaster medicine training for physicians that should be included in the curricula in medicine. The statement provides that furthermore:

> *[…] physicians are confronted with an exceptional situation in which their normal professional ethics must be brought to the situation to ensure that the treatment of disaster survivors conforms to basic ethical tenets and is not influenced by other motivations. Ethical rules defined and taught beforehand should complement the individual ethics of physicians [WMA 2006]*

Codes of Ethics for Nurses

In 1953, the International Council of Nurses (ICN) adopted an International Code of Ethics for nurses which was recently revised in 2005:

> *'Nurses have four fundamental responsibilities: to promote health; to prevent illness, to restore health and to alleviate suffering […]. Nursing care is respectful of and unrestricted by considerations of […] disability or illness, sexual orientation, nationality, politics, race […] [ICN 2005]*

The American Nurses Association (ANA) provides a 'Code of Ethics for Nurses – Provisions' which was approved in 2001:

> *'The nurse, in all professional relationships, practices with compassion and respect for the inherent dignity, worth and uniqueness of every individual, unrestricted by considerations of social or economic status, personal attributes, or the nature of health problems' [ANA 2001]*

These provisions do not explain 'the nature of a health problem' but nurses may practice unrestricted in caring for clients, as both codes illustrate.

In summary, contemporary ethical standards for HCWs provide less guidance regarding the extension of the duty to care for patients in epidemics.

What is the right starting point for public health ethics? The following chapters treat the evolution of public health ethics beginning with a historical view of the roots of ethical principles that guided medical practice.

2.3 The Evolution of Public Health Ethics

2.3.1 The Origin of ‘Social Medicine’ as the Traditional Concept of Public Health

Since Hippocrates (460-377 B.C.), medical practice has been orientated to the individual, while at the same time considering environmental conditions. Hippocrates was the first physician to treat patients in a practice based on ethical principles and considering the concept of social medicine. It is a particular concept of medicine which includes ethical claims such as the promotion of health as a primary duty of the physician – a promotion that pays attention to the public environment, its heredity affecting health, and as well, as the possibility that individual problems of health and illness may also communal aspects [Viseltear et al. 1997, p.60]. Auspicious as this concept may have been, the insights of Hippocrates were not strong enough to change the direction in medicine towards preventive measures on the population level. Instead, medicine remained rigidly curative and was characterized by its incapacity to react to epidemics in an appropriate way. In the Middle Ages diseases were explained through religious and superstitious ideas such as the occurrence of epidemics as punishment by God or illness as ‘something evil’ [Brennecke and Schelp 1993, pp. 1-9].

With the coming of the French Revolution, the relationship of people changed concerning individual dignity, individual rights, and class differences. The process of decision-making was also challenged. About 150 years ago, rapid industrialization, with its growing urban regions, gave birth to the beginning of social medicine as it was called in Europe, or public health. This era was associated with poverty, bad living conditions, short life spans, death, and an increased occurrence of plagues, especially among the working class. The government failed to introduce appropriate measures in the new, crowded cities. This led to the need to deal with social conditions in general and with the relevance of the social aspects of medicine in particular [Bloom 2002, pp.11-22].

From the beginning, the practice of social medicine has depended on health information, and information, in turn, requires the existence of surveillance systems and organized data. In England, Friedrich Engels was a pioneer of social medicine with his description of ‘The Condition of the Working Class in England’ in 1844; Edwin Chadwick (1800-1890) with his work, which instituted the beginning of the sanitary movement in Britain with consequences of dramatic improvement in public health. At this time William Farr (1807-1883) developed statistical methods for measuring morbidity and mortality; and John Snow (1813-1858), the ‘father of epidemiology’, identified the cause of cholera by descriptive methods. He removed the handle of the contaminated Broad Street pump from where cholera was spreading. Snow’s activity was a landmark in public health intervention – the first to contain the spread of an epidemic [Bloom 2002, pp. 11-22].

In Germany, social medicine was formed by the ideas of Peter Johann Frank (1745-1821), a pioneer of social hygiene who advocated a comprehensive system of health surveillance as part of his ‘Medizinische Gesundheitspolizey’; and later by Rudolf Virchow (1821-1902), Robert Koch (1843-1910), and Alfred Grotjahn (1869-1931) all of who studied living conditions in relationship to the state of health of the poor, which is described below [Brennecke and Schelp 1993, p. 5].

The following chapter can be seen as an illustrative example of social and political disorder at a time when mainly the economic interests of politics came more to the fore than the protection of the public’s health. The typhus epidemic in Upper Silesian and the cholera epidemic in Hamburg, both in the 19th century provided a tool for social, economic and political analysis which would have been useful for new emerged infectious diseases such as SARS, too.

2.3.2 Public Health, Plagues, and Politics

Upper Silesian Typhus Epidemic in 1848

One pioneer of social medicine needs to be highlighted, namely Rudolf Virchow. He investigated the Upper Silesian typhus epidemic in 1848 and played an important role in designing social structure in society.

Virchow identified the influence of poverty and occupation on the general state of health and concluded that the causes of the epidemic were a complex of economic and social factors in the absence of democratic structures. He underlined the requirement of a more human orientation in medicine – not only therapy but also prevention measures implemented by the government. According to Virchow is medicine a social science [Bloom 2002, pp.11-22]. Instead of recommendations for changes in medicine, he focused on a program of social reconstruction and the consolidation of new values, namely, the right to education, political and religious freedom, and the ‘right to health’ including the duty of the state to provide welfare to reach it [Bloom 2002, Shryock 1947, pp. 171-202]. This brought on the introduction of systematic structures for public health, including effective sanitation and sewage systems. Concerns of lifestyle and behaviour were addressed to everyone in the society – to the ill as well as the healthy and also to the health authorities. [Viseltear et al. 1997, p. 38].

The Cholera Epidemic in Hamburg in 1892

The cholera epidemic in Hamburg swapped over from Asia to Europe due to increased trade and industry [Evans 1987, pp.226-7]. A major cause of the disaster was seen in the trade interests of governmental authorities who were able to suppress the epidemic at first and announced information of an outbreak with a time delay [Evans 1987, pp.508-9]. The official announcement of an outbreak in Hamburg led to imposing extensive quarantine measures and health checks on the ships of trading partners. The local authorities forcibly disinfected refugees, or refused them shelters or deported them. The economic impact during the epidemic in Hamburg was remarkable. ‘The weekly gross turnover was 50 million Marks earlier, now it is only a few thousand’ [Evans 1987, pp.372-6].

Jews were held responsible for the cholera epidemic. Hamburg was infected by ‘the corrupting bacillus of Judaism’ [Evans 1987, pp.389-91]. Parallel in New York, quarantine was imposed on Jewish immigrants under the premise of protecting the health of the public [Mitka 2003].

When cholera appeared in Hamburg in 1892 the causative agent was unknown. The physician and public health reformer Robert Koch convinced public authorities that cholera was transmitted by unfiltered water, and concomitants like poor housing conditions and insufficient sanitation which are linked to social inequality and the absence of constitutional democracy. It had been realized that not quarantine and isolation were successful in containing the spread of cholera but improving living conditions [Shryock 1947]. Koch spread medical education by providing society with mass leafleting, and giving information about hygiene. The cholera epidemic generated great pressure for social and political reforms [Evans 1987, pp.470-3].

In retrospect, in the 19th century, the revolutionists of social medicine enforced reforms in controlling and preventing infectious diseases. They defined concrete socio-political requirements referring to ethical claims such as health promotion and disease prevention. According to Rudolf Virchow, ‘health is politics, and politics is health’ if it matters to people [as cited in Banerji 2004]. Even though the relevance of social medicine showed an important relationship to disease and social conditions, the pioneers of public health did not find the appropriate acceptance of their new programs because the bacteriological discoveries, which were expected to solve ‘all’ medical problems, dominated the revolution of social medicine [Bloom 2002, pp. 11-22; Eckhart 1998, pp. 305-6].

The following part presents the relationship between public health and human rights. It sets out the relevant human rights that should be considered in developing strategies for infectious disease control.

2.3.3 Public Health and Human Rights

Even though human rights have a long history; attention was given anew to human rights after the Second World War. In 1945 the United Nations created a charter between nation states to embody a ‘Declaration on the Essential Rights of Man’ [International Bill of Human Rights 1996]. In 1946, in conformity with the Charter of the United Nations, the Constitution of the WHO declared, ‘the right to health’ to be a fundamental human right and stated that ‘good health is a state of complete physical, social and mental well-being, and not merely the absence of disease or infirmity [WHO 2006].

Parallel to this in 1947, due to the experience with Nazi Germany, the Nuremberg Code was constituted as a starting point for respecting fundamental human rights in human subject research. This includes principles such as ‘informed consent’ and the absence of coercion, adequately formulated scientific experimentation, and beneficence to participants. Later modified, and still the basis for contemporary guidance, with the Declaration of Helsinki by the World Medical Association in 1964 for guiding physicians in biomedical research involving human subjects [Nuremberg Code 1949; Declaration of Helsinki 1964].

In 1948 the world community considered that the United Nations Charter insufficiently expressed the rights it propagated. Therefore the Universal Declaration of Human Rights [1948] was adopted as a standard obligation that ‘all human beings are born free and equal in dignity and rights’. The right to health is explicitly expressed in Article 25 of the Declaration. In 1966, this declaration was divided into two conventions due to Cold War politics.

The International Covenant on Economic, Social and Cultural Rights (ICESCR) expresses ‘the rights to the highest attainable standard of health, work, social security, adequate food, clothing and housing, education, and the right to enjoy the benefits of scientific progress and its applications’. The steps for realizing the ‘right to health’ should include ‘the prevention, treatment and control of epidemic, endemic, occupational and other diseases’ [ICESCR 1966].

The International Covenant on Civil and Political Rights (ICCPR) includes ‘the rights to liberty, to security of person, to freedom of movement, to vote, and not to be subjected to cruel, inhuman, or degrading treatment or punishment or to arbitrary arrest or detention’ [ICCPR 1966]. Together with the United Nations Charter and its successor the Universal Declaration of Human Rights, these four resolutions can be seen as the ‘International Bill of Human Rights’ [1996]. Even if the ICESCR and the ICCPR do not have the power of international law, they are a forceful normative tool for promoting human rights in the global community [ICESCR 2006]. An important fact is that nearly every article of the resolutions has implications for health.

Despite the obligation of governments to ensure the preconditions for health and to provide medical care, there are some situations where it is legitimate to restrict human rights in order to protect the health of the public. According to the ICCRP, individual rights can be overridden ‘to (…) secure public order, and the general welfare; and in times of emergency when there are threats to the vital interests of the nation’ [ICESCR 1966; Gruskin and Tarantola 1997].

But certain restrictions cannot be taken by public health authorities without considering less intrusive alternatives. For defining the extension of permitted restrictions and legitimate action the *Siracusa Principles* on the Limitation and Derogation Provisions in the ICCPR, adopted in 1984, provides a useful guideline Public health measures that infringe on civil and political rights 'must be prescribed by law; be applied in a non-discriminatory manner; relate to a compelling public interest in the form of a significant infectious disease risk to the public health's health; and be necessary to achieve the protection of the public, meaning that the measure must be based on scientific and public health information and principles; proportional in its impact on individual rights to the infectious disease threat posed; and the least restrictive measure possible to achieve protection against the infectious disease risk' [Siracusa Principles 1984].

The Universal Declaration of Human Rights has influenced many international conventions; and is the basis for decisions of national and international tribunals [Working Group Four 2006]. Since the founding of the United Nations more than 50 years ago, the relationship between health and human rights development has increased constantly since then.

When new-emerged infectious diseases came more to the fore, so did ethical issues associated with it which will be illustrated with the HIV/AIDS epidemic in the next part.

HIV/AIDS Epidemic and the Impact of Neglecting Human Rights

In 1967 the US Surgeon General W.H. Stewart was convinced that 'it was time to close the book of infectious diseases' [as cited in Garrett 1994]. The occurrence of HIV/AIDS proved the opposite. These new emerged epidemic has brought competing interests into the limelight and started an ethical debate. It presents a major challenge to public health and human rights as well as SARS continued.

When HIV/AIDS first appeared in America, it was considered as a disease that affected minority groups because it was associated with 'the '4-H' patients: homosexuals, haemophiliacs, Haitians, and heroin addicts' with the accompanying consequences of limited control and fewer prevention measures [Emanuel 2003; Des Jarlais et al. 2006].

It was the first time in more than a generation that HCWs were confronted with a serious health threat [Singer et al. 2003]. The uncertainty of transmission and the absence of any effective treatment for HIV/AIDS brought the issue of the duty of professionals to treat contagious patients into the limelight. Two generations of physicians had not had any experience with serious epidemics [Huber and Wynia 2004]. Many HCWs cared for patients even at personal risk, while others refused to care for them. These reasoned that HIV/AIDS patients deserved their infections due to their lifestyles. Others argued that no one can force a HCW to care for a patient with HIV/AIDS [Emanuel 2003]. Education gradually decreased the fear of HCWs and increased their willingness to provide treatment to HIV patients [Tzeng 2004].

In 1981, in the beginning of the AIDS epidemic, surveillance consisted of the reporting of names for each new confirmed case for a better monitoring of prevalence and incidence without consideration for the right to privacy and confidentiality [Bayer and Fairchild 2004]. The consequences may have been included the loss of work, accommodation and finally liberty. AIDS activists pushed decision-makers to consider individual rights to privacy, and autonomy as well as the right to justice in the distribution of health care resources [Smith et al. 2004].

In 1987, it was the first time that human rights were included in a health strategy of the WHO with the global response to AIDS [Gruskin and Tarantola 1997]. The Office of the United Nations High Commissioner for Human Rights [1998] and the Joint United Nations programme on HIV/AIDS stated that experiences with enforced public health measures were unproductive because they led to ’drive away people most in need of services and failed to achieve their public health goal of prevention through behavioural change, care and health support’. It was observed that fewer people became infected while protecting human rights. In fact, no public health policy that violated the rights of individuals could be effective in controlling an infectious disease. These arguments led to a change of surveillance but it took years.

In 1999, the Centers for Disease Control and Prevention (CDC) recommended the use of unique identifiers instead of using names for notified cases [Bayer and Fairchild 2004].

The HIV/AIDS pandemic was, and is a promoter of uncovering the interdependence among politics, public health and human rights and has provided a new starting point in the ethical debate on infectious diseases – because human rights are a foundational element of ethics.

The next chapter presents a set of general moral considerations that strengthen the rights of individuals. It illustrates the way we look at contemporary ethical principles.

2.3.4 Public Health Ethics in the Light of Biomedical Ethics

Moral commitments to protecting individual health go back thousands of years. Since the time of Hippocrates (5th century B.C.) to modern times, medical practice has been orientated on ethical principles. Traditionally, the Greek Hippocratic Oath, when seen in its original form, prescribes a set of standards of medical function and has built the basis for guiding the relationship between physicians and patients. It contains, above all others the principle of nonmaleficence expressed in the maxim '*Primum non nocere'*, the principle of beneficence expressed in '*Salus aegroti suprema lex'*, as well as confidentiality and justice [Bauer 2006; Calman and Downie 1997].

In the 1960s, the 'traditional' medical ethics based on the Hippocratic Oath turned into the new path of bioethics. The 'new bioethics' focused on life-extending procedures, the use of reproductive technology or genetic biotechnology, to name just a few. It was no longer clear what is beneficial and what is harmful and how the resources in health care should be distributed, and who should make such decisions? Bioethics was born with some of the principles inherent of the old medical ethics but covers more participants than medical ethics ever had [Jonsen 1998, pp. 11-2; Calman and Downie 1997].

The following set of moral clusters: respect for autonomy, nonmaleficence, beneficence, and justice builds the basis for the 'principles of biomedical ethics' developed by Tom L. Beauchamp and James F. Childress [2001] in 1979. These principles provide guidelines for professional ethics and can function as an analytical framework for decision-making. They can be, and frequently are, in conflict. There is no absolute order of priority in these four principles and the weights vary in different circumstances.

(1) Principle of Respect for Autonomy

The principles of nonmaleficence and beneficence have provided throughout the history of medical ethics a basis for paternalistic actions toward patients. In the 1960s, with the appearance of the patients' rights movement, influenced by the exposure of abuses in medical research and the democratization of society after the Second World War, the concept of 'respect for the patient's autonomous decisions' and 'informed consent' was established. People wanted to be involved in decisions which were going to affect them [Calman and Downie 1997; Jonsen 1998, pp. 11-2].

'Respect for Autonomy' requires obligations to build up capacities for an autonomous choice while helping to remove conditions like fear that could have an influence on the autonomous action. Respect implies enabling a person to act autonomously, and acknowledging his right to decision-making. The principle of respect for autonomy is specified and appears in some rights and obligations of liberty, privacy, confidentiality, truthfulness, and informed consent. No individual should be obliged to participate in research or medical treatment without informed consent that contains competence, voluntariness, disclosure, recommendation, understanding, decision, and authorization. If a patient is not competent to make his own choice, then for example a hospital, a physician, or a family member may justifiably make the decision instead. This is called surrogate decision-making. The Quinlan process in 1976 was the starting point for establishing standards of surrogate decision-making. [Beauchamp and Childress 2001, pp. 57-112; Calman and Downie 1997].

(2) Principle of Nonmaleficence

The principle of nonmaleficence is expressed in 'above all do no harm' which implies the premise of protecting persons against some types and levels of harm, and avoid causing harm to them. Furthermore the principle is specified into some moral rules, for example: 'Do not kill; Do not cause pain or suffering; Do not incapacitate; Do not cause offense; Do not deprive others of the goods of life.' There exists no clear differentiation on the continuum from not inflicting harm to providing benefit. In the case of the principle of beneficence there is a need to take positive steps to help others, and not only refrain from harming them [Beauchamp and Childress 2001, pp. 113-64].

(3) Principle of Beneficence

The principle of beneficence refers to a moral obligation to act for the benefit of others. One famous example of beneficence is presented in the parable of the Good Samaritan in the New Testament. Beauchamp and Childress [2001, pp. 165-224] examine two principles of beneficence: *positive beneficence* which requires agents to provide benefits, and *utility* which requires that agents balance benefits and drawbacks to produce the best results overall.

The principle of positive beneficence supports a spectrum of rules and obligations to protect and defend the rights of others; to prevent harm from occurring to others; to remove conditions that will cause harm to others; to help persons with disabilities, and to rescue persons in danger. According to David Hume, the obligation to benefit others grows from social interactions and is called *'Reciprocity'*. When a single person receives the benefits of society, it therefore ought to promote the interests of society [Beauchamp and Childress 2001, pp. 165-224].

The principle of utility requires the determination of the particular action that produces benefit. It is limited to balancing the benefits, risks and costs of probable outcomes of actions in order to achieve the highest benefit, which is sometimes called *'proportionality'*. The principle of beneficence is applied in clinical medicine as well as supporting public beneficence through health policies. These policies reflect the reasoned choice of an action or program for example about appropriate benefits in relation to risks and costs. These decisions ought to be based on the most reliable data [Beauchamp and Childress 2001, pp. 165-224].

(4) The Principle of Justice

Due to issues concerning the fairness of distribution in resource allocation the concept of justice appeared. There is a minimal formal requirement common to all theories of justice which is attributed to Aristotle: 'Equals must be treated equally, and unequals must be treated unequally' [Beauchamp and Childress 2001, pp. 225-82].

Problems of justice which refer to fair, equitable, and appropriate distribution of health care arise under conditions of scarcity or competition. There exist several theories which serve to determine the distribution of scarce resources, for example the utilitarian, the libertarian, the communitarian, or the egalitarian theory which underlie all different conceptions.

Beauchamp and Childress [2001; pp. 225-82] propose that society has a right to a ‘decent minimum’ of health care within a scope for resource allocation that implies both utilitarian and egalitarian standards.

Regarding justice, it is important to distinguish between equity and equality. Equity is about fairness and justice, and judgements need to be made in relation to society as a whole. It means that everybody should have an opportunity to attain health. Factors which might be avoidable raise issues of equity such as access to health care services. Questions of fairness in resource allocation raise important ethical issues for public health. Factors influencing health which are unavoidable belong to equality. For example, biological variations as sex, age, or race [Calman and Downie 1997].

According to Beauchamp and Childress [2001], the biomedical ethics have the function of identifying and analysing ethical problems. The biomedical ethics have been applied in dealing with physician-patient relationships while less attention has been given to the public.

2.3.5 Concepts in Public Health Ethics

Public health is ‘what we, as a society, do collectively to assure the conditions for people to be healthy’ [Institute for Medicine 1988]. Public health ethics consider professional practice regarding to groups of people whereas the ethics of medicine is concentrating on interpersonal relationship between physician and patient. Until recently, the society has been paying more attention to ethics of medicine than for public health and so far, there is no agreed-upon framework. Some contrasting positions and views in and proposals of frameworks for public health ethics are provided in this chapter.

Wehkamp [2004], proposed the four principles of biomedical ethics by Beauchamp and Childress as a pragmatical tool for application in any situation where competing interests are at play for identifying and analysing ethical dilemmas. Even though the principle of ‘justice’ is related to meso- and macro-level, Wehkamp established additionally the principle of ‘equity’ as a fifth principle in respect to a more comprehensive view.

According to Wehkamp, adequate decisions in infectious disease control for SARS-like diseases, basically, need ethical fundaments. Because epidemics need quick responses, the biomedical ethics with its four principles are applicable and easy to handle in such situations. To strike a balance between protection of public good and protection of individual rights, these principles will be a starting point for public health ethics. The four biomedical principles have to be transformed to the collective level and individual and collective interests have to be evenly matched as follows: *(1) Autonomy of the patient – Autonomy of citizens; (2) Beneficence for the individual – Beneficence for populations; (3) Nonmaleficence towards individuals – Protecting societies; and (4) Justice – Equity.*

Donnan [2003] has termed the biomedical ethics 'four principles of ethical debate and behaviour' and related them to a population perspective. The ethics of public health ought to be the ethics of political activity and decision-making. The participation of each individual in society is a paramount issue of public health practice because ethical principles will have no meaning in public health unless they consider the values and principles of all people in the public health field.

Calman and Downie [1997] provide an overview of ethical principles that are relevant to the improvement of the health of populations in any country. They concluded that ethical issues, for example related with social and economic problems, the level of education of the population, the way of resource allocation, the organization of health services, and the national and international importance of health legislation, can be discussed in terms of the traditional bioethical principles: non-maleficence, beneficence, respect for autonomy, and justice. In addition, in respect to resource allocation problems, the principle of utility should be taken into consideration.

Abelin and Jeanneret [1996] recommend the biomedical ethics as a framework for public health. Biomedical ethics, partly, is only applied to the individual level whereas the approach to a wider spectrum as an ethics for the health sector as a whole includes much more scopes. For Abelin and Heanneret the interest in health and ethics need to be extended beyond the interpersonal relationships at micro-level; ethical considerations have to be included at the meso-level of institutions, and at the macro-level of nations, international as well as global relations.

Childress et al. [2002] have mapped the terrain of public health ethics. Because public health ethics has focused more on practice than on theory, concepts, methods, and so forth remained mostly undefined. They provide several moral considerations in relevance to issues in public health and concrete them for guiding action as follows: justice or fairness, respect for autonomy and liberty, and privacy and confidentiality. To the question of how to resolve conflicts, Childress et al. responded with five ‘justificatory conditions’ that are useful in determining whether the promotion of public health overrides individual rights: effectiveness, proportionality, necessity, least infringement, and public justification.

Bayer and Fairchild [2004] believe ‘that the standard appropriate to public health cannot be derived from the basic assumptions of a bioethics dominated by individuals.’ The writers provide a set of controversies implicating the concepts of liberty, privacy, and paternalism to examine the deep divide between the commitments of bioethics and the values for public health practice. Bayer and Fairchild clearly advice that for shaping an ethics of public health, bioethics is the wrong starting point.

Callahan and Jennings [2002] pointed out that ethical problems raised by public health, require their own ethical analysis beyond the borders of bioethics. They provide specific types of ethical analysis of which one or more of them might be appropriate for any ethical problem: professional ethics, applied ethics, advocacy ethics, and critical ethics. The authors recommend continuing ethics education for public health practitioners in this field. Because of a wide range of the work in this profession, from private managed care organizations and clinics to international nongovernmental organizations and federal, state, and local agencies, the efforts in education prove to be difficult.

According to Roberts and Reich [2002] biomedical ethics is discussed and taught to medical students, but a comparable ethics of public health for guiding public health practitioners does not exist. Roberts and Reich provide a method for describing and analysing the main ethical ideas inherent in discussions of public health policy. Their framework includes three philosophical views. The first focuses on outcomes (utilitarianism); the second on rights and opportunities (liberalism), and the third position on views that emphasises character and virtue (communitarism). Roberts and Reich concluded that health professionals need skills in applied philosophy for improving transparency, coherence and quality in advising the public on ethical issues in health policy.

Kass [2001] stated that medical and research ethics give a high priority to an individual's autonomy which cannot be appropriately transferred to public health practices. Kass propose a framework for an ethics analysis of public health programs. It is not a code addressing general norms and expectations of professional behaviour. It is an analytical tool to consider the ethical implications of interventions such as policy proposals, research, and programs. The 6-step framework asks these questions: '(1) What are the public health goals of the proposed program? (2) How effective is the program in achieving its stated goals? (3) What are the known potential burdens of the program? (4) Can burdens be minimized? (5) Is the program implemented fairly? (6) How can the benefits and burdens of a program be fairly balanced?' Kass require these ethical analyses for gaining the public's trust and for furthering social justice and the health of the public.

Thomas et al. [2002] provide a code of ethics for public health in response to new technological advances which create new possibilities and imply new ethical dilemmas due to challenges such as the emergence of HIV; and to abuses of power such as the Tuskegee study of syphilis. For Thomas et al. the concerns of public health are not the same as those of medicine why the principles of biomedical ethics cannot simply translate to public health. The code of 12 ethical principles, written for public health institutions, focuses principally on public health practice, was the first explicit statement of ethical principles inherent to public health. According to the Thomas et al. the document could fit on one page and be easily posted: (1) Public health should address principally the fundamental causes of disease and requirements for health, aiming to prevent adverse health outcomes; (2) Public health should achieve community health in a way that respects the rights of individuals in the community; (3) Public health policies, programs, and priorities should be developed and evaluated through processes that ensure an opportunity for input from community members; (4) Public health should advocate for, or work for the empowerment of, disenfranchised community members, ensuring that the basic resources and conditions necessary for health are accessible to all people in community; (5) Public health should seek the information needed to implement effective policies and programs that protect and promote health; (6) Public health institutions should provide communities with the information they have that is needed for decisions on policies or programs and should obtain the community's consent for their implementation; (7) Public health institutions should act in a timely manner on the information they have within the resources and the mandate given to them by the public;

(8) Public health programs and policies should incorporate a variety of approaches that anticipate and respect diverse values, beliefs, and cultures in the community; (9) Public health programs and policies should be implemented in a manner that most enhances the physical and social environment; (10) Public health institutions should protect the confidentiality of information that can bring harm to an individual or community if made public. Exceptions must be justified on the basis of the high likelihood of significant harm to the individual or others; (11) Public health institutions should ensure the professional competence of their employees; (12) Public health institutions and their employees should engage in collaborations and affiliations in ways that build the public's trust and the institution's effectiveness.

Levin and Fleischman [2002] required the utility of ethical analysis in responding to emerging public health challenges like the outbreak of the West Nile Virus (New York). The development of the response to involved judgements about the seriousness of the condition, the level of risk, of the harm to populations at risk, the appropriateness of possible interventions, the costs of alternative interventions, the relevance of public concerns, and the consideration of competing public health needs. Levin and Fleischman mentioned that these ethical analyses would be useful for explaining such value considerations and examining the basis for decision-making.

2.4 Global Political Response, the SARS Epidemic and Ethics

Have the lessons from epidemics in history been instructive enough to ensure that past prejustice will not repeat? The answer to this question provides the next paragraph with a summary of the evolution of a newly emerged infectious disease, the SARS epidemic. How SARS has affected the health of the global public, and how the global public health has responded to the crisis reveals global implications for human rights, and introduces some basic information about SARS.

Basic Information about SARS

The aetiology of SARS is thought to be a *corona virus* (SARS-CoV). SARS is transmitted from person-to-person, mainly by respiratory droplets. In the beginning, it meant dealing with an extremely contagious disease of which the scientific knowledge of cause, pattern of transmission, diagnostic test and treatment were unknown.

As is typical of an emerging disease, no vaccine was available and no immunological experience within the population [Galvani 2004]. The success of containing the transmission of SARS was attributed to traditional public health measures as well as to global cooperation [Kian and Lateef 2003].

The next section highlights the raising of ethical issues in the SARS control of 2003. Some issues are underlined by included parts of a speech or newspaper, out of a case study.

The SARS Epidemic

‘Anyone who has read the history of public health feels trapped in a time machine and transported back to the nineteenth century…’ [Kickbusch 1997].

In November 2002, the new virus emerged from southern China and spread around the world. According to WHO [2003b], worldwide a total of 8,422 people became infected of which 916 died. 20% (1,725) of all cases occurred in HCWs. SARS was contained in early July 2003.

Starting Point in Mainland China

On 16th November 2002, the first case of atypical pneumonia was reported in Guangdong province in China. The first human victims probably contracted SARS through contact with an animal that carried a mutated virus able to cross the species barrier. The first information about a rapidly spreading atypical pneumonia in Guangdong province came from journalists on 10th February 2003 through media, and not from the health officials’ side. Nevertheless, some media reports produced panic and hysteria instead of keeping the public with objective information well-informed [Yuen and Zhong 2005].

> *‘When such a right (free press) is firmly in place, the activities of those in power come under public scrutiny, thus government and officials become publicly accountable for what they do and therefore are more likely to work to higher standards.’ [Spiess 2003]*

In China, the maintaining of public order has priority as a respiratory specialist mentioned who was involved in an advisory committee for epidemic diseases:

> *‘You foreigners value each person’s life more than we do because you have fewer people in your countries. Our primary concern is social stability, and if a few people’s deaths are kept secret, it’s worth it to keep things stable’ [Department of Health 2003].*

Cases of severe atypical pneumonia had been reported for two months in five cities in Guangdong Province without anyone paying attention. Hong Kong Special Administrative Region (HKSAR) and Guangdong missed the exchange of information because of a ‘one country - two systems’ situation. In China, from November 2002 to February 2003, 305 cases were reported of which 105 were HCWs with an atypical pneumonia whose causative agent was unknown [Yuen and Zhong 2005]. Even though information was incomplete, experts suggested that there were two respiratory diseases simultaneously occurring in Guangdong Province in the late November 2002, influenza A and SARS [Heymann 2003].

> *‘In order to ensure stability as the nation’s two annual legislative assemblies got underway, hospitals officials were forbidden to publicize what they’d learned about SARS’ [Time Magazine 2003].*

The Chinese government held on its authoritarian roots despite its willingness to contain SARS and cooperate with international authorities. In May 2003 a regulation was passed declaring that all citizens of China faced penalties such as imprisonment or execution in the case of breaching quarantine and spreading disease intentionally [Ries 2004].

> *‘The SARS crisis is a warning to government that it should modernize the way it operates. In the past, when crisis occurred, the government used to tackle them by trying to play down their repercussions to maintain social stability, which was their top priority. However, this tactic did not work with the SARS outbreak’ [Spiess 2003].*

SARS had already spread to other parts of the country. In Beijing, only twelve cases were reported. Similarly a retired doctor was informed by colleagues that the number of cases was many times higher than officially stated. He passed this information on to international magazines and the international community was alerted. The data were updated by Chinese authorities and raised to 792 cases of which 31 died. Beijing’s officials cover up information till 20th April despite pressure for cooperation [WHO 2003a].

> *‘On April 3rd, China’s Minister of Health announced to the press that the Chinese government was already diligently dealing with the problem of SARS, and that the spread of the disease was already under control…*

> *…The next day when the retired doctor went to the hospital all doctors and nurses who had seen Zhang's (Minister) statement were furious. As a doctor who cares about people's lives and health, I have a responsibility to aid international and local efforts to prevent the spread of SARS…' [Time Magazine 2003].*

In mainland China and Taiwan on the one hand the media created panic, fear, stigmatization, and discrimination, and the government had no control over media, on the other hand, there was a lack of information when the government could control the media [Hsin and Macer 2004]. The Nobel Prize-winning Harvard economist Amartya Sen noted regarding freedom of the media the following:

> *…no substantial famine has ever occurred in a democratic country – no matter how poor. This is because famines are extremely easy to prevent if the government tries to prevent them, and a government in a multiparty democracy with elections and free media has strong political incentives to undertake famine prevention [Sen 2000].*

Global Spread

From the entry into the international community in Hong Kong on 21st February, SARS moved on to infect 29 countries within four months. In mid-March 2003, SARS was first recognized as a global threat [WHO 2003a]. Some of the hot spot areas outside of Mainland China included Hong Kong, Vietnam, Taiwan and Canada [Heymann 2004].

Hong Kong Special Administrative Region

In Hong Kong, a total of 1,755 people were infected, and 300 died. Among the infected, 22% (n=386) were HCWs [WHO 2003c].

The index patient of the epidemic in HKSAR, and likely of the pandemic, was a medical professor from Guangdong Province where he had treated patients in his home town. He stayed at the Metropole Hotel in Hong Kong to attend a family wedding on 21st February and transmitted the disease to guests and visitors within 24 hours [Yuen and Zhong 2005].

There was poor communication and transparency in the initial stage of the crisis among Mainland China authorities and HKSAR despite a lot of requests for information, only little was shared. On 10th March the unknown disease was a topic of an emerging epidemic on the front page of Hong Kong's newspapers [Chan 2004].

> *'Overall, the epidemic in Hong Kong was handled well, although there were clearly significant shortcomings of system performance during the early days of the epidemic when little was known about the disease or its cause'.*
>
> *'The really difficult challenge in such situations is how to convey messages in a way that is open, honest, clear and sympathetic, and at the same time not likely to be proved wrong. There is a delicate balance between keeping the public on the alert and trying to reassure the public and alley fear' [SARS Expert Committee Summary Report 2003].*

At the End of March health authorities in Hong Kong used barricades and tapes for quarantining a housing complex and placing its residents under quarantine for SARS but many residents had fled, leaving more than half of the units occupied [Mitka 2003; Ries 2004]. The following day residents were moved to a camp outside the city (outset) [SARS Expert Committee Summary Report 2003].

> *Nevertheless 'Draconian measures such as compulsory quarantine were deliberately avoided at the outset because of concern about driving SARS patients into hiding. There were also concerns about issues of civil liberty and public acceptability, whether or not such control measures would be effective (or might aggravate the risk of spread of disease), and the feasibility of enforcement' [SARS Expert Committee Summary Report 2003].*

The disease spread further on to hospital systems of Hong Kong, Viet Nam, and Singapore and around the world along the routes of international air travel.

Vietnam

According to WHO, a total of 63 individuals became infected of which five died. 57 % (n=36) of the affected cases were HCWs [WHO 2003b].

On 28th February 2003, Dr. Carlo Urbani, a WHO expert based in the office in Vietnam, received the order to investigate a patient at the French Hospital in Hanoi who has stayed days before at the Metropole Hotel in Hong Kong. After his admission, about 20 hospital staff became ill with similar symptoms [National Advisory Committee Canada 2003]. Dr. Urbani informed the WHO of the severe acute respiratory syndrome and closed the hospital. Four weeks later he died of SARS.

In mid-March, the WHO alerted the global world and instituted global surveillance and recommended travel advisories and screening measures at airports for passengers departing from areas with local transmission [Tsang et al. 2003].

> *Gro Harlem Brundtland [2004]: 'We were lucky that this man (Urbani) was contacted, was knowledgeable, was courageous. He quickly taught hospitals how to react. We issued a global alert very quickly…this was the first global alert the WHO has ever made'*

Two days after the global alert, the government provided Vietnam National Television and other media with information about the new disease to keep the public well informed of prevention measures.

> *In October 2003 the Minister of Health stated that 'The public need to understand how to protect themselves and their help is needed to detect suspected cases in the community so that they can be quickly isolated. Public education also reduces the chance of panic and social disorder' [Minister of Health of Vietnam 2003]*

According to Chan [2004] the officials acted despite its communist system in a remarkable transparent way during the epidemic, kept the society informed, and cooperated with WHO openly. Astonishingly, Vietnam was one of the first countries to contain the spread of SARS within 45 days. At the end of April Vietnam was removed from the list of infected countries by WHO.

> *The BBC reported the developments in Vietnam as follows: 'Vietnam's government had taken all the right action – from international cooperation and openness about issue, to training health care workers about the symptoms' [BBC News 2003].*

Taiwan

In mid-June, a total of 665 people in Taiwan became infected – of which 180 died. 13% (n=86) of the cases were related to HCW [WHO 2003b]. The Taiwanese government complained about heavy economic and human costs. Because of Taiwan's status as a renegade province, the Taiwanese apparently were unable to cooperate with WHO. All official communication went through Beijing [Chan 2004].

> *‘‘For many years, the People’s Republic of China has unreasonably opposed to Taiwan’s joining the World Health Organization. Recently it has concealed information about a SARS outbreak in China, to result in a sudden global epidemic…This is how China ‘looks after Taiwan’ [Government Information Office 2003]*

The first case was identified in mid-March. At the end of March, a Taiwanese resident of Hong Kong’s Amoy Garden flew and took the train to Taiwan and infected other passengers. In April, one visitor of the Metropole Hotel from Hong Kong visited Taiwan even though he should have been under home isolation. He was the probable source of a major outbreak in Taiwan [Tzeng 2004].

> *‘China is a country where politics always interferes with health matters. In China, not only disease information is not transparent, epidemics are often left alone without proper management. Such incompetence in disease control brings harms to the health of its own people and that of the world population as well’ [Government Information Office 2003].*

Canada

Canada was the country hardest hit by SARS outside Asia. It has an immigration link with Hong Kong. SARS was recognized first in mid-March, and by June a total of 251 people had become infected, of which 41 died. 43% (n=108) of all cases affected HCWs [WHO 2003b].

The first cases in Toronto were a married couple of Hong Kong descent who lived in Toronto. They visited relatives in February 2003 and stayed in the Metropole Hotel in Hong Kong at the same time as the medical professor from whom the pandemic had originated [Poutanen et al. 2003]. She was the index patient in Toronto and died a week before the WHO alerted the world. Family members became infected and transmitted the disease to various hospitals [Svoboda et al. 2004].

Ontario implemented strict guidelines in all hospitals and security staff and police helped to enforce the restrictions. Public health officials utilized voluntary quarantine and isolation measures to control the spread of SARS. In only a small number of cases did quarantine orders need to be legally enforced [Gostin et al. 2004].

In a society where people experienced such freedom, questions were asked as to whether a system can persist in such an emergency. As a result of media attention, additional cases were identified [Poutanen et al. 2003].

> *'Things are not working according to our normal procedures. It's quite extraordinary. The fact that SARS information supplied to (hospitals) changes daily poses deep challenges' [Hall et al. 2003].*

People were denied access to services of the health care system, even when the services were vital. There were furthermore, discrepancies between decisions made at the frontline and those made by public health authorities [Bell et al.2004].

> *The New York Times reported: 'Prime Minister Jean Chrétien and Mr. Lastman, Toronto's mayor, have come under increasing criticism in recent days for not taking stronger action to confront the health or even making a concerted effort to calm fears' [Krauss 2003].*

When SARS was finally brought under control, the government and health authorities stated that they had not been prepared for such an epidemic.

> *'Vaccines, sanitation, medical improvement and antibiotics reduced the burden of infectious disease, shifting patterns of morbidity and mortality from diseases like diphtheria to diseases like coronary heart disease' .*
>
> *'The shift in public health priorities to long-term population health promotion, coupled with the general decline in public and governmental attention to infectious disease control, has led to the point where our public health system is not well equipped to deal with significant outbreaks of a new communicable disease' [SARS Commission 2004].*

Within four months, on 5th July 2003, the SARS epidemic was declared by the WHO to be over [WHO 2003a]. While SARS has already been contained, however, human rights issues still persist. The evolution of the SARS crisis in comparison with the emergency response strategies of differing political systems draws out various implications for international human rights. Decision-making should be based on updated scientific knowledge and ethical considerations in strategies for infectious disease control.

'A wise man, therefore, proportions his belief to the evidence'

David Hume (1711-1776)

2.5 Ethical Questions arose from SARS Epidemic

In public health, ethical issues arise primarily between the rights of individuals and the responsibilities of the state to promote and protect the health of the society as a whole, - or in other words, to further the well-being of others. SARS provides several examples of contemporary challenges for public health that pose ethical questions - of which a few are presented here:

The protection of public health necessitates the restriction of certain human rights. The question is how public health should be protected and also balanced with individual rights?

Was the individual’s right to health adequately protected by the International Covenant on Economic, Social and Cultural Rights considering such loss of life?

Are governments required to take all precautionary measures to contain emerging infectious diseases regardless of costs and social disruption? Who should be the judge of such things?

Had some countries applied infection control measures, such as quarantine, too extensive to contain SARS?

Are there circumstances that call for a need to breach privacy and confidentiality despite the far-reaching consequences of discrimination of individuals and groups?

Are HCWs obliged to provide care to patients when their own health could be put in jeopardy? Is the duty of health care workers unlimited in providing care for patients?

Should a country be made responsible for suppressing health information with global interest, even though the international legal obligations under the IHR were to report epidemics of cholera, plague, and yellow fever?

A free and courageous press is the spine of democracy. How important is a free press when confronting an infectious disease?

How can the global community initiate active steps to protect the health of its citizens while stabilizing the world order?

These ethical questions need a clear communicated and accepted political response, so that, when faced with a future pandemic, health authorities can deal with the impact of the ethical concerns of which some were mentioned above.

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4 Aim of the Diploma Thesis

There is a strong relationship between ethics, public health and politics. SARS forced a re-evaluation of the political response to infectious diseases with pandemic potential. To understand this relationship it is necessary to gain an insight into *‘Ethical Issues in SARS control’*. This work provides an overview of the identified ethical issues in the SARS control management. A discussion of it with respect to differing political systems is provided, as well as recommendations for developing more effective and appropriate strategies in controlling future epidemics of SARS and SARS-like diseases.

5 Manuscript for Publication

Ethical Issues in SARS Control

Background: Severe acute respiratory syndrome (SARS) started out as a newly emerged infectious disease and spread rapidly around the world. Besides social and economic disruption, SARS caused high morbidity and mortality, especially in health care workers (HCWs). SARS challenged the political response to containing the spread of disease. Decision-making in a time of uncertainty was associated with a high potential for ethical conflicts during the SARS epidemic.

Objective: The aim of this analysis is to identify and discuss ethical issues in SARS control based on experiences undergone during the SARS epidemic in 2002/03.

Methods: A systematic literature review was undertaken from 11/2002 until 3/2006 by using PubMed with ‘SARS and ethics’ as search terms. The identified ethical issues were categorized in issues of clinical ethics; public health ethics, and global health ethics.

Results: 46 articles were retrieved, of which 30 articles met the criteria of relevance. The frequency of identified ethical issues was related 48% to clinical ethics; 35% to public health ethics; and 17% to global health ethics. Eleven main ethical issues were identified: (1) Duty of HCWs to care for patients vs. duty to care for themselves to minimize the risk of transmitting disease to others; (2) Duty of HCWs to care for patients vs. duty of health care institutions to maximize the safety of HCWs; (3) Duty of HCWs to care for patients vs. equality between HCWs during an epidemic; (4) Duty of physicians to act in the best interest of individual patients vs. physician’s responsibility to the public rather than to individual patients in emergencies; (5) Priority setting in health care institutions (collateral damage) vs. equity; (6) Common good of public health vs. individual liberties; (7) Information needed by the public to contain the spread of disease vs. privacy and confidentiality of information; (8) Risk communication through media vs. creating fear and panic; (9) Containing the global spread of SARS vs. economic losses; (10) Global solidarity vs. suppressing health care information with global interests; (11) Global solidarity vs. intellectual property rights.

Discussion: Ethical issues are less considered in the analysis of infectious diseases. SARS highlighted ethical conflicts. *Clinical ethics* demonstrated the duty of HCWs to care for SARS patients. Worldwide 20% of all cases occurred in HCWs.

In Canada, there was generally appropriate personal protective equipment (PPE) whereas in Asian countries (except Singapore) the duty to care was mostly involuntary and with less PPE. Less information and education about the disease was associated with more fear and less duty to care for SARS patients. Furthermore priority setting was a difficult issue that faced hospitals during the SARS epidemic and changed the needs of patients. The collateral damage in people without SARS may be as high as in people with SARS. *Public health ethics* described quarantine from voluntary application as in Canada where people accepted these control method to compulsory measures in Asian countries were people reacted with fleeing or hiding. The consequences of violating the order were threats of imprisonment or execution as China and Taiwan demonstrated, and social disorder and limited infection control. Regarding risk communication, a well-informed public is more likely to voluntary comply with measures recommended by health officials who are perceived knowledgeable and reliable to contain the spread of disease. Control strategies were less successful because people that feared stigmatization and discrimination likely avoid seeking medical care and remain undetected in community which has important consequences for disease control and prevention. Global solidarity is concerning *global health ethics*. From a judicial point of view, the International Health Regulations (IHR) were recently restricted to three infectious diseases – cholera, plague, and yellow fever – when SARS emerged. In case of an outbreak, the aim is to eliminate the source of infection, to stop transmission, to apply prevention measures if necessary, and to maintain the health of the public. From an ethical point of view, every nation has a responsibility for cooperation and global solidarity, not only for justice but to ensure the health of the own nation. The intellectual property rights have not been an ethical issue in SARS control; they will be one of equity for the future.

Key words: Ethics, SARS control, infectious diseases, public health, decision-making, policy, biomedical principles

Introduction

In November 2002, a new *coronavirus* caused the severe acute respiratory syndrome (SARS). It emerged from Southern China and spread around the world. SARS had an enormous economic impact and caused social disruption far beyond the affected countries due to insecurity in dealing with a disease without scientific knowledge [24]. According to WHO [47] 8,422 people worldwide became infected, of which 916 died. SARS is unique in recent history in its rapidity of transmission, its concentration in health care settings, and the large number of infected health care workers (HCWs) who made up with approximately 20%, most of the secondary victims [48].

SARS showed how vulnerable countries can be if exposed to a global health risk and why it is important to assist public health work in preventing and controlling the spread of infectious diseases by rules, regulations and laws. Most infectious diseases are preventable and treatable. The success of containing transmission of SARS was attributed to traditional public health measures some of which infringed on individual rights while protecting the health of the population [49]. There have been many situations in which two or even more competing interests have come into play. In these times of uncertainty, decisions were made with limited information and short deadlines. Decision-making between individual freedoms and the public good raised ethical conflicts. The report of the Working Group of The University of Toronto Joint Centre for Bioethics [34] dealt with the experience of the SARS epidemic in Canada. The ethical conflicts provided by this group were used for identifying three main categories: (1) Clinical ethics; (2) Public health ethics; (3) Global health ethics for literature review.

However, even SARS was not behaving like the next great pandemic; experts expect a global influenza within the next decade [34], which would probably have an effect on economics and societies similar to that demonstrated by SARS.

The aim of this study is to provide an overview of ethical issues related to the management of SARS and SARS-like diseases based on experiences encountered during the SARS epidemic of 2002/03. An evaluation of the ethical issues caused by SARS control may support decision-makers in formulating effective control strategies against SARS and SARS-like diseases with pandemic potential to be better prepared for the future.

Methods

Data Sources and Study Selection

The methodology known as a systematic review was utilized [50]. For identification of relevant literature the database ‘PubMed’ was used with the search term ‘SARS and ethics’, from 11/2002 until 3/2006.

The study selection included all literature describing ethical issues in controlling SARS according to the criteria of relevance. A publication was judged to be relevant if it expressly mentioned components of SARS, ethics, and control measures or public response to SARS. The quality of the reviewed publications was not assessed. Literature identified in PubMed is listed first in the reference list [1-46].

One publication was additionally included because it builds the response to a brief article listed in the PubMed database [43]. Articles published after 29th March 2006 were not considered. One study was excluded because it was conducted before the SARS outbreak [22]. Literature that had no human context [4]; and no relation to SARS control measures [3, 11; 13; 16; 28; 32; 39]; as well publications of less than one page [1; 25; 41; 44; 45; 46], and a double publication [36] in different journals were excluded from review.

Data Extraction and Synthesis

Two types of procedures were used to analyze the literature. To address the scatter of the literature, a checklist was used for scanning: name of the journal; to what field the publication belongs; the type of publication; and to the types of category the ethical issues belong to, either global health ethics; public health ethics; or clinical health ethics.

To address the research question concerning the identification of ethical issues in SARS control, the second procedure categorized the ethical issues into three main groups: (1) Global health ethics; (2) Public health ethics; (3) Clinical health ethics. The findings were summarized by qualitative description of the ethical issues; the extension they applied; the strategies used for containing the spread of SARS; and the reaction of people involved in control measures applied by authorities.

Two independent reviewers scanned the literature relevant for review on the basis of a checklist. The scatter of the literature and the identified ethical issues were agreed on through a consensus process with the second reviewer, as well as the qualitative descriptions by which the control measures were applied.

Results

A total of 46 publications available in PubMed were identified. After titles and articles were scanned to assess their relevance to ethical issues in SARS control, 30 papers (65%) were judged to be relevant for this review. 16 were excluded as they did not provide descriptions of ethical issues in controlling SARS.

Concerning the literature scatter, 20 papers (67%) were located in the field of medical or clinical care, five papers (17%) focused on public health and law. Four publications (13%) concerned ethics, and one paper (3%) issued law, medicine & ethics.

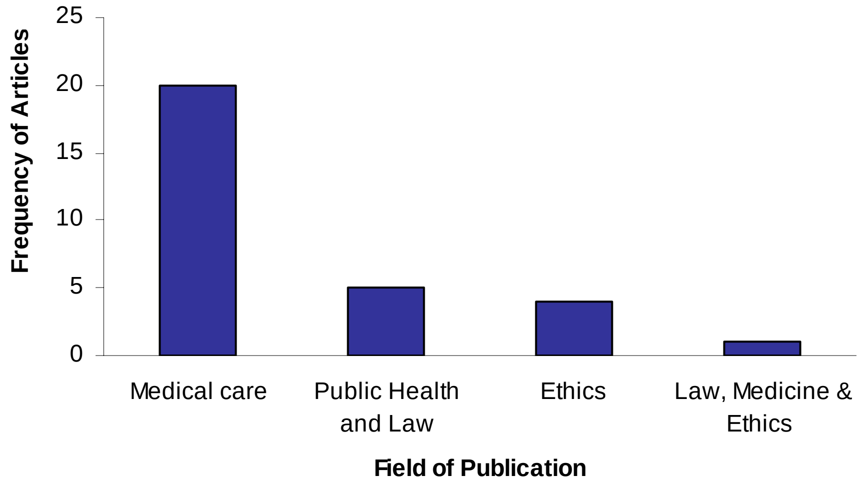

Figure 1: Frequency of included articles relating to various fields between 11/05–3/06

Each publication was classified as to its type. From 30 papers, fifteen (50%) were articles; eight papers (27%) concerned comments, letters, editorial, and supplements; the remaining seven (23%) were reviews.

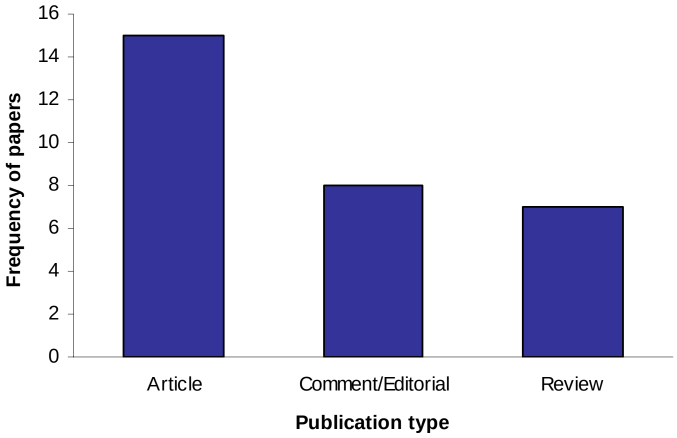

Figure 2: Total number of reviewed papers by publication type between 11/02-03/06

The most common type with 25 (83%) belong to theoretical, five (17 %) to empirical publications. The quality of the reviewed publications was not assessed.

The review process yielded a corpus of 30 articles concerning the identification of identifying ethical issues in SARS control. The frequency of ethical issues was related 48% (n=55) to clinical ethics; 35% (n=40) focused on public health ethics; and the remaining 17% (n=19) to global health ethics. Some publications covered more than one topic. Overall, the literature of this review is characterized by an emphasis on clinical issues rather than public health or global health issues.

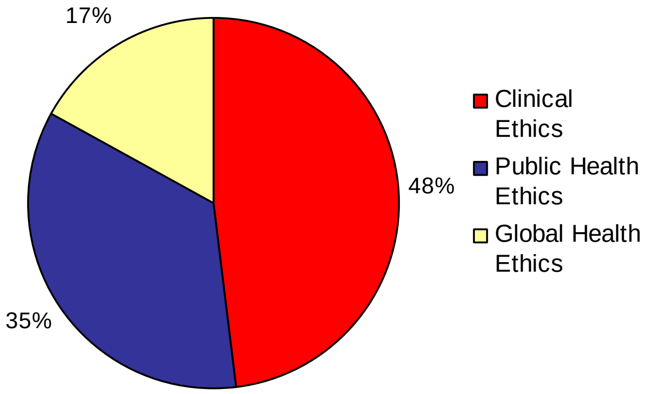

Figure 3: Frequency of identified ethical issues in percent by groups

Eleven main ethical issues were identified and categorized into three groups: (1) Clinical ethics; (2) Public health ethics; (3) Global health ethics.

Clinical Ethics

- Duty of HCWs to care for patients versus
    - duty to care for themselves to minimize the risk of transmitting disease to others
    - duty of health care institutions to maximize the safety of HCWs
    - equality between HCWs during an epidemic
- Duty of physicians to act in the best interest of individual patients versus
    - physicians' responsibility to the public rather than to individual patients in emergencies;
- Priority setting in health care institutions (collateral damage) versus
    - equity

Public Health Ethics

- Common good of public health versus
    - individual liberties
- Information needed by the public to contain the spread of disease versus
    - privacy and confidentiality of information
- Risk communication through media versus
    - creating fear and panic

Global Health Ethics

- Containing the global spread of SARS versus
    - economic losses
- Global solidarity versus
    - suppressing health care information with global interests
    - intellectual property rights

Clinical Ethics

The absence of specific treatment or vaccination against SARS implicated an increased risk for HCW, who have been the most common secondary victims [27, 35]. The duty to care and risk for staff who were caring for patients with contagious diseases produced considerable anxiety and psychological distress [19, 21, 42].

(1) Duty of HCWs to care for patients versus duty to care for themselves to minimize the risk of transmitting disease to others

A health care professional has a duty to care for patients even at great personal risk, based on several ethical considerations, e.g. professional codes; and accepted risk as a part of doing a specific type of work. Moreover HCWs have a responsibility to protect both their own health and the health of others while caring for patients.

During the SARS epidemic the duty of HCWs to care extended from demonstrating altruism to refusing to care for SARS patients. The reaction of HCWs varied from voluntary care for SARS patients, as in Canada [8], from refusing to treat SARS patients, as in Israel [8], to resigning from their jobs and punishing those who were afraid of treating SARS patients, as in China and Taiwan [21, 37], to receiving large sums of money as in Taiwan to care for SARS patients, to nurses who were taught to be obliged to provide care [37]. In Taiwan, most doctors and nurses died from taking involuntary care for SARS patients, and some physicians were punished by the retraction of their professional license for not having detected hospital infections [21]. The consequence of quarantining a hospital in Taiwan was the escape of 25 physicians and nurses [9, 21].

In Singapore, HCWs were dedicated to providing care in the SARS units [9] All doctors continued working – “life was valuable not money” [30].

(2) Duty of HCWs to care for patients versus duty of health care institutions to maximize the safety of HCWs

Although the risk was low for the general public, many infections broke out among unprotected HCWs who had had direct contact with the respiratory secretions of SARS patients [38]. Health care institutions have a reciprocal duty to provide safe working environments for HCWs under risk in order to maximize the safety of not only the HCWs and patients, but also to ensure the health care.

In China, Hong Kong and Taiwan [17, 21, 37], HCWs neglected to stay on their job, this, for fear of becoming infected due to the inadequacy of their personal protective equipment (PPE). Toronto and Singapore provided the distribution of PPE and announced plans to compensate HCWs who had sacrificed salary because of SARS [30, 33, 38]. In Canada, emergency medication was provided for HCWs before the arrival of the national stockpile [14].

(3) Duty of HCWs to care for patients versus equality between HCWs during an epidemic

Which HCWs should be involved in health threats like SARS with regard to their age, sex, marital status, or pregnancy? [8, 21] As Toronto and Hong Kong noted, nursing students were not allowed to care for SARS patients due to safety considerations, lack of insurance, and less competence for crises [17, 18, 38]. In Toronto, staff that was non-essential where sent home with pay [18]. Pregnant and immunosuppressive staff where redeployed to low-risk activities or sent home, as in Canada [18].

(4) Duty of physicians to act in the best interest of individual patients versus physicians' responsibility to the public rather than to the individual patients in emergencies

In emergencies coercive measures may be an appropriate intervention such as testing, treatment, vaccination, or quarantining patients [6, 7]. Physicians play an important role in communicating these measures. The primary responsibility of physicians in emergencies is to work closely with public health while still acting, to a possible extent, in the best interest of patients. Frontline physicians will face ethical dilemmas when patients disagree with public health measures such as rationing or quarantine [6].

(5) Priority setting in health care institutions (collateral damage) versus equity

The allocation of scarce resources such as treatment, medicines, hospital beds, staff, equipment, and prevention measures, if available, is an important issue in public health and linked to decisions by governments and the health care sector [18, 38]. SARS was a test of the capacity of every facet of the various health care systems [9, 20, 40]. Health authorities designated special infectious disease hospitals as units for SARS patients [2, 18, 31]. Hong Kong declared a standstill of routine surgical services [19]. Shortages of HCWs led to overwork [37, 38].

Canada announced, that thousands of people were being denied access to medical services – sometimes for life threatening diseases. It became apparent that patients with no access to medical care might die or might be irreversibly compromised by the postponing of urgent tests, treatments or limitations on operating times [42, 33]. An investigation conducted in three hospitals in Toronto found, that 1050 surgeries had been cancelled because of SARS. ‘There may be as many people who died from other illnesses and could not get into hospital as there were who died from SARS’, the University of Toronto Joint Centre for Bioethics stated [34].

Other collateral damage included psychological distress that was suffered by both patients, with and without SARS, and HCWs [42].

Public Health Ethics

(6) Common good of public health versus individual liberties

This conflict in society describes the tension between protecting the public’s health and protecting individual rights to liberty that were restricted by quarantine and isolation. People that were quarantined experienced restriction of movement, loss of pay, and sometimes also loss of occupation and home, as well as no access to services of the health care system, even if they were vital. A number of countries that were affected by SARS resorted to extreme measures from voluntary to compulsory quarantine or isolation to contain the spread of disease.

In Canada, and mostly in Singapore, quarantine and isolation measures were applied voluntarily [10; 14], and job protection, loss of income, and the like – due to SARS – were compensated [10, 33, 38]. Singapore described compliance as a necessary precondition for an effective containment of infectious diseases and used surveillance cameras and electronic monitoring for enforcing quarantine [9, 10].

Other countries affected by SARS such as China, Hong Kong, Taiwan, and India also used quarantine as an effort for containing the spread of disease. In Beijing and Taiwan, hospitals quarantined staff and patients without any warning and preparation, causing massive panic and escapes from the hospital [9, 21, 31]. In China and Taiwan, authorities enforced quarantine and isolation with threats like imprisonment and execution for those who violated the order [10, 26]. In Hong Kong, barricades and tapes were used to quarantine a large housing complex from which people fled [10, 21].

In India, quarantine was enforced while banishing people into hospital without informing them with consequences of escaping from hospital [2]. The application of enforced quarantine and isolation measures resulted in mass panic.

In Israel where no infections were confirmed, the measures were preventive. Nevertheless these measures were applied restrictively and without consideration for the ethical committees in hospitals which are legitimated in the “Israeli Patient’s Rights Act” [8].

People experienced marginalization, discrimination and stigmatization by society – especially Chinese people and HCWs – with long-term psychological consequences [9, 14, 21].

(7) Information needed by the public for containing the spread of disease versus privacy and confidentiality of information

Public health laws require physicians to report cases of notifiable infectious diseases like SARS. Furthermore, surveillance and contact-tracing are essential for containing the spread of disease. In the interest of the public good, there may be times when health information must be shared publicly and in doing so, may impinge on individual rights to privacy, confidentiality, and respect for autonomy with informed consent.

In Toronto, the index patient of Hong Kong descent was publicized with informed consent of the family [31, 34]. In Asia, contact tracing was applied without any informed consent. Likewise in Israel, with no confirmed case, examinations and treatment were established without informed consent [8]. In Singapore (with the aid of the military) and Hong Kong (with the aid of police) contact-tracing was undertaken in an aggressive way [31]. In Singapore, the names of superspreaders were made public: one patient received the information that she was the index patient on television, as well as in the newspapers [9, 31]. In India, besides the names, addresses, occupations, and family details of the patients were reported in the media. Furthermore, newspaper reporters camped in front of a nursing home to capture nurses under quarantine on camera [2].

Singapore observed that infection control becomes more problematic when it intrudes on privacy and that the enforcement of measures was less a problem when it was carried out in public places [9]. Screening with thermal scanners was applied before entering official and residential locations as well as entry into airports. Monitoring with web cameras, regional barriers; the ring fence concept, and tag surveillance (sign outside the house) were all experienced by those under home quarantine [9, 31].

People, not only patients and their families but also HCWs, experienced marginalization, stigmatization and discrimination by society as consequences of quarantine and isolation [9]. It had consequences for Chinese communities as well, by avoiding Chinese businesses, not only in North America with economic - and social impacts [31, 34].

(8) Risk communication through media versus creating fear and panic

Fear, especially of the unknown, can influence the behaviour of people tremendously. Therefore the method of informing the public of adverse circumstances is very important. How to strike a balance between producing insecurity, fear and panic and creating a well informed public?

'Many patients were less sick to death than scared to death' [8]. The element of anxiety and hysteria was dominant in societies. Media reports in Canada and in Asian countries contributed to confusion, fear, stigma and discrimination in their sensationalizing of world events [21, 37, 42]. China, Taiwan, and India experienced mass panic created by narratives spread through media. People became psychologically and socially isolated by their friends and relatives [2, 21].

But without media serving as a means of educating the populace, the death toll everywhere would have been higher [21]. In Singapore, information about infection control measures such as hand washing, using masks, disinfection, and eating habits to strengthen the immune system, were provided by the public. This disseminated a basic knowledge of how to assess the risk of spreading disease and its containment. An education program on television was installed [9].

Global Health Ethics

(9) Containing the global spread of SARS versus economic losses

Infectious diseases accompanied with high morbidity and mortality raise issues of economic responsibility in the global community to uphold conditions that contain the infections and control and prevent further spread with consequences not only for individuals but for whole regions. The International Health Regulations (IHR) of the World Health Organization (WHO) were used to issue emergency travel advisories for several cities in the world that were affected by SARS to restrict travel and contain the spread of disease with severe economic impacts.

The WHO recommended in April 2003 "the toughest travel advisories in its 55 year-history" to high risk SARS areas [7, 9, 26, 39, 40] with tremendous worldwide economic impacts estimated to be about US$100 billion [24]. All travellers of international departures were screened for symptoms of SARS to prevent the spread of SARS from outbreak areas [31]. The Centers for Disease Control and Prevention (CDC) recommended less restrictive measures after understanding the science of SARS [31].

(10) Global solidarity versus suppressing health care information with global interests

The legal obligation for a WHO member state to report information of specific infectious diseases to ensure maximum security against the international spread of diseases is based on the IHR. Every country has a responsibility to share health information in order to maintain global public health. China suppressed information of atypical pneumonia [33, 34, 40].

(11) Global solidarity versus intellectual property rights

Intellectual property rights have not been an issue in SARS control but may be a future problem of public health, especially with patents for the SARS virus and the genome. Due to the ideal global collaboration, the causative agent of SARS and the sequence of its genome were identified in a month.

Researchers from Canada, USA, and Hong Kong applied for a patent on the SARS genome. With a patent on the SARS genome, probably not everyone will have access to the results for developing drugs or vaccines. Furthermore it will have an influence on further research on SARS [43].

If there is a new vaccination available, what side-effects would be acceptable? Paediatric research that may be without benefit will be important for future research on vaccines against diseases like SARS. It is important to balance the risk and benefits on children in vaccine research against infectious diseases like SARS to maximize their safety [23].

Biomedical research entered the global world to improve public health benefits. The current ethical principles that govern research with human subjects do not consider the research on health problems in resource-limited settings as developing countries are [29].

Discussion

Traditionally the study of infectious diseases has focused on scientific and medical issues. Ethical issues are less considered. The search in PubMed yielded 46 entries of the phrase ‘SARS and ethics’ while a search of ‘SARS’ led to 3,822 entries [PubMed, 29.03.2006].

The literature research was limited to the PubMed database that may imply a publication bias restricted to language, topic, and geographical aspects, and to a specific period of time. It should be taken into account that some publications issued ‘SARS and ethics’ may have been missed as well as the relatively small number of reviewed publications. It must be noted that the selection process is inherently subjective.

While SARS has already been contained many ethical issues still persist. The purpose of this literature review is to examine ethical issues in political response undertaken to cope with SARS. The frequency of ethical issues was related 48% to clinical ethics; 35% to public health ethics; and the remaining 17% to global health ethics. Eleven main ethical issues were identified, of which some will be discussed.

Clinical Ethics

Duty to care for SARS patients

According to the WHO [47], worldwide 20% of all cases occurred in HCWs. The duty of HCWs to care for SARS patients depended on various aspects. In Canada, there was, in general, appropriate PPE and the care for patients continued, whereas in Asian countries (except Singapore) the duty to care was mostly involuntarily and with less PPE. In return, there is a reciprocal obligation to protect and support HCWs on the part of health care institutions.

Less information and education on the disease was associated with more fear and less duty to care for SARS patients. In Singapore, educational programmes on television and personal training were applied [9, 14]. In addition, Toronto and Taiwan illustrated how important communication and education are in the midst of an epidemic to keep the public well informed. Providing nurses with education about SARS increased their knowledge and contributed to positive attitudes regarding their willingness to care for SARS patients, a study in Taiwan pointed out [17, 24]. Hong Kong describes the promotion of professional identification for nursing students subject to educational activities [17].

There is a duty to care – mainly determined by professional ethics [5, 27, 41]. Furthermore, in choosing their life's work HCWs accept the risks and challenges of their professions. Many professions have inherent occupational hazards, and professionals cannot resign from their job and their responsibility even when there is a more extraordinary than expected. For example, fire fighters do not have the freedom to choose between a harmless and harmful fire [33, 34]. But a fire fighter is at all times aware of his potential risk and will have been trained for emergencies with appropriate PPE. Otherwise he would not be allowed to do his job. According to Working Group Three for WHO [51] the majority of HCWs, particularly in the developed world, have less awareness of their potential risk of contracting an infectious disease. Furthermore, according to Reintjes 'infectious diseases are different; they are infectious' [52]; a person can be both a victim and a vector [7].

How to draw a line between the self-protection of HCWs and the neglect of duty to determine an adequate scope of care that has to be accepted as a standard to meet the duty of caring for patients in epidemics? What level of risk can be accepted for HCWs? This investigation does not answer these questions. The Joint Centre Group for Bioethics in Toronto also could not reach a consensus on the issue of the duty to care regarding the extent to which HCWs are obliged to risk their lives in delivering medical care [34]. In addition, Sokol [53] called for a continuing discussion on this topic due to the competing obligations inherent in HCWs multiple roles, which influence the limits of their duty to care.

Priority setting

Priority setting is a difficult issue that faced hospitals during the SARS epidemic and changed the needs of patients. It also deals with limited financial resources. The collateral damage in people without SARS may be as high as in people with SARS [34]. There was a discrepancy between the decisions made at the frontline and those made by public health authorities. It also implicates changes in patients' needs and restrictions for patients with and without SARS, and for hospital staff [18]. National pandemic influenza preparedness plans in Europe were evaluated by Mournier-Jack and Coker [54]. No plans provided descriptions belonging to priority setting by which people will be identified as a priority group.

In the case of a future pandemic, human and material resources of health care will be limited and every recommendation to ration a resource holds the possible consequence of causing human suffering or even loss of life. Wiesing and Marckmann [56] require that the maintenance of an appropriate health care should have priority. Kotalik [55] demands from open democratic societies that decision-making should not be a task for experts only, but a task which involves those who will be most affected.

Public Health Ethics

Quarantine and Isolation

SARS-affected countries used isolation and quarantine from voluntary as Canada described were people accepted the measures to compulsory measures in Asian countries where people reacted by fleeing or hiding. The consequences of violating the order were imprisonment or execution, as China and Taiwan demonstrated, as well as social disorder and limited infection control [57]. With SARS and also with future epidemics like influenza, the way that quarantine and isolation was handled, is a critical ethical issue.

Day et al. [58] and Schabas [59] are consonant with the excessively use of quarantine during the SARS epidemic. It was implemented without considering whether the intervention would be helpful in reducing the spread of the disease even though it meant dealing with a newly emerged disease. Mass quarantine led to significant social and psychological disruption and economic costs without improving the detection of infected individuals.

The WHO Writing Group [60] and Bell [18] circumstantiated that evidence and experience suppose that aggressive isolation and quarantine would likely be ‘ineffective, not a good use of limited health resources, and socially disruptive’. Such interventions should be implemented while respecting human rights and diverse cultures, then they would be less burdensome. The evaluation of national pandemic influenza preparedness plans made by Mounier-Jack and Coker [54] revealed that the enforcement of quarantine and isolation would be mandatory by 14 of the 25 European countries.

In Western countries control measures for infectious diseases are regulated by law. Fidler [61] stated that for containing the spread of SARS by governments, the use of quarantine and isolation infringe not *per se* on civil and political rights. Governments need to fulfil certain conditions prescribed in the *Siracusa Principles* before interference with international human rights laws on public health grounds. The public health response to SARS or SARS-like diseases should be reviewed under this law; the application of control measures should be the least restrictive measures [57, 61]. According to Gostin [14] public health laws empower officials to quarantine individuals suspected of being exposed to an infectious disease like SARS. The exercise of this power need to be guided by ethical principles.

DiGiovanni et al. [62] investigated factors influencing compliance with quarantine in Toronto. The results require the essential need for a consistent quarantine policy including procedures and public messages within jurisdictional borders. Barbera et al. [63] pointed out that a well-informed public is more likely to voluntarily comply with measures recommended by health officials who are perceived as knowledgeable and reliable in containing the spread of disease.

The response to infectious diseases in different societies depends on social conditions, social values and political contingencies [9]. Markel [14] noted that Singapore authorized quarantine and isolation which mostly restricted suspected disease carriers’ freedom. This authority complements their cultural experience. Singapore led this back to the crisis mentality and the strong social discipline of the people [9].

Toronto and Beijing both quarantined about 30,000 people. Beijing had 2,500 cases and Toronto 250. The CDC estimated that in Beijing only one-third of the people that were quarantined had a serious risk of contracting the disease. When comparing this estimation with the SARS cases in Toronto, quarantine was used more often in Toronto than in Beijing [10]. Nevertheless the introduction of voluntary quarantine in Toronto was very effective, with widespread compliance [14].

Nowadays modelling is able to determine the conditions under which quarantine is expected to be an adequate tool while considering the infectiousness of a disease which is based on the basic reproduction number [58, 60, 78].

For guiding decision-making in public health policies, scientific evidence and its interpretation play an important role in control strategies. Without considering scientific knowledge like the causation of a disease or the efficacy of implemented interventions, decisions would be based on uncertainty and probably fail their moral purpose of promoting and protecting the lives of citizens [66].

Furthermore the implementation of quarantine was accompanied by psychological states of mind such as anxiety, depression and posttraumatic stress disorder. These consequences were also observed in Toronto by Hawryluck et al. [64] and in Hong Kong by Wu et al. [65].

Announcing of private information

Surveillance and contact tracing are essential public health measures. The right of confidentiality of health information may be overridden by naming names, and naming communities in view of the public's duty to protect the society from serious health risks. As demonstrated by the HIV/AIDS epidemic, control strategies were less successful than expected because people that fear stigmatization and discrimination likely avoid seeking medical care and remain undetected in the community – which circumstance has important consequences for disease control and prevention [67]. The handling of publishing information in Asian countries proved the failure of control and prevention by political response – which circumstances hold consequences for the global society.

Risk communication

Risk communication of unpredictable health threats through the media is an important means of reducing panic and keeping the public well informed. The importance of a free and courageous press, as the spine of democracy on the one hand, and the production of mass panic and stigmatization through sensationalising on the other hand, is a critical ethical issue in epidemics.

The perceived risk of SARS was many times higher than the actual risk was [68]. The appearance of infectious diseases often produces fear in individuals and panic in populations. Fear especially of the unknown, has a strong influence to people's behaviour, as newly emerged diseases and minority groups such as the Chinese were introduced to the world during the SARS epidemic [69].

Even though, in Canada, quarantine and isolation was implemented voluntarily, some critics suggested that ‘the public will not accept quarantine measures’. This proves how important an effective communication is for reaching public trust and participation in political response to an infectious disease [14].

According to Barbera et al. [64] the transfer of effective information to society is an important way of suppressing their anxiety and encouraging community support.

The results achieved by Mounier-Jack and Coker [54] showed, for future pandemic influenza preparedness plans in Europe, that some countries will develop communication strategies at later stages of a pandemic. But as Sandman and Lanard [70] as well as Wiesing and Marckmann [56] stated, it is the aim of pre-pandemic communication to help the society get ready for the future. And the best time to discuss potential risk is *before* the pandemic.

Global Health Ethics

Global Solidarity

Is there a moral obligation to inform other countries and international institutions about health risks? SARS demonstrated that local events become global events. Is the behaviour of China to hide health information with global interest acceptable or does it create any responsibility under the IHR? From a judicial point of view the IHR were recently restricted to three infectious diseases - cholera, plague, and yellow fever - when SARS emerged. There was no international legal obligation under the IHR for WHO member states to report SARS because this infectious disease and also HIV/AIDS were not mentioned in the regulations. Therefore the international agreement on infectious diseases has had no relevance for the SARS epidemic to WHO member states [61]. SARS demonstrated that the situation in other countries may affect the global society. In the case of an outbreak the aim is to eliminate the source of infection, to stop transmission, to apply prevention measures if necessary, and to maintain the health of the public. From an ethical point of view every nation has a responsibility for cooperation and global solidarity, not only for justice but to ensure the health of their own nation [40].

Intellectual Property Rights

The Trade-Related Aspects of Intellectual Property Rights (TRIPS) agreement of the World Trade Organization and public health became controversial with the limited access to pharmaceutical products in developing countries [61]. The TRIPS agreement is able to set out compulsory licensing to patent owners in case of an emergency which allows developing countries and countries that have no production capacity access to patented products in a fair manner [71]. According to WHO [72] the effects that patents on SARS will have – such as diagnostic tests, drugs and vaccines and their availability, will be monitored in order to avoid burdens on efforts related preventive measures and treatment that should be available to all.

According to Working Group One [73], for the WHO, the research on vaccination should be applied in a fair manner, especially in the case of children who are not able to agree by informed consent. Furthermore, the group pointed out that the side-effects of a new vaccination do not contribute to the trust in people to use the opportunity of vaccinations which will limit the success of preventing an infectious disease because of less herd immunity. Even if intellectual property rights have not been an ethical issue under SARS control, they will be one of equity in the future.

SARS stimulated a critical re-evaluation of public health strategies for infectious diseases. The WHO [74] provides a checklist for preparing for an emergency. This included explicit ethical issues. Questions that need to be addressed are: ‘Have ethical aspects of policy decisions been considered? Is there a leading ethical framework that can be used during the response to an outbreak to balance individual and population rights?’ In order to be prepared for future influenza epidemics, many countries have developed a preparedness pandemic plan. According to the draft of Working Group Four [75], for the WHO, which addressed ethical issues in pandemic influenza planning, most countries did not note ethical issues.

Recommendations after SARS

The SARS epidemic taught us some important lessons about ethical considerations which can be useful in the handling of epidemics. These lessons can support decision-makers in developing appropriate and effective strategies against SARS and SARS-like diseases with pandemic potential to ensure that infectious disease control is not only a method for preventing and treating infectious diseases but also a path towards creating public health.

- Politics should be paying more attention to ethics in infectious diseases.
- Educational activities with greater emphasis on infectious diseases for health care professionals, especially the targeting newly emerged ones, would be a helpful tool in coping with SARS-like diseases.
- Increased emphasis on workplace safety is important. The expectation of the duty of HCWs to care for patients with SARS or SARS-like diseases requires maximizing their safety through health care institutions and governments, such as appropriate PPE, providing medicine or vaccinations if available, as well as education and training in infectious diseases to manage emergencies and to ensure adequate care.
- The collateral damage due to priority setting and limited resources is unavoidable during an epidemic like SARS, even though decisions must be as equitable as possible between SARS patients and the requirements of an epidemic as well as the interests of other patients. This is and will be a challenge for health care professionals in epidemics.
- Quarantine and isolation should be regulated by infectious disease laws which imply the application of the least restrictive measures. Effective infection control requires the consideration of updated scientific knowledge, modelling; as well as surveillance. Political response should be based on evidence and experience, not on uncertainty.

- Communication in the sense of dialogue and not only transferring information is a key element in ethics during epidemics. To reach every citizen in the midst of an epidemic, communication, education and transparency provide the key to achieving trust and solidarity which are essential. Communication of health information should be applied with respect to privacy – and risk communication with the aim of preventing fear and panic while keeping the public well-informed.
- In order to achieve global solidarity, cooperation in matters of transparency and information-sharing is very important for both social stability and economic growth.
- In the future, Intellectual property rights should not be an obstacle to accessing virus or genome sequences of infectious diseases like SARS. With respect to equity, every nation should have the means of protecting the health of its population.
- There is a need for an active debate about fundaments of public health ethics to be prepared for a quick response in case of SARS-like diseases. Ethical considerations in infectious disease control will be not only a more human, but also a more efficient guide that can support decision-makers in creating policies at all levels; that can not avoid, but balance conflicts. According to Wehkamp [76] is '*ethics the art of decision-making*'.'

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6 Appendix

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FAKULTÄT LIFE SCIENCES – Forschungsschwerpunkt Public Health

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Ethical Issues in SARS Control

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SARS – „It‘s a big success story“ Gro Harlem Brundtland; former WHO director general

Background

- Infectious diseases are different, they are infectious! An individual can be both, a victim and a vector
- Global spread of SARS due to international trade and travel
- SARS took the society back to a pre-therapeutic era
- Decision making was associated with a high potential for ethical conflicts during the SARS epidemic

Objective

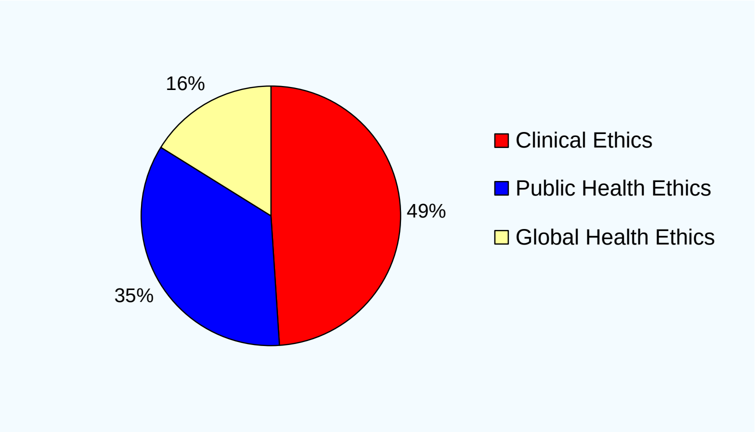
- To examine ethical issues of the public health response undertaken to control SARS

Methods

- A systematic literature review (46 articles retrieved by PubMed, using ‘SARS and ethics’ as search terms, from 11/2002 until 3/2006; 30 articles met the criteria of relevance)
- Categorizing the identified ethical issues into three main groups: (1) Clinical Ethics; (2) Public Health Ethics; (3) Global Health Ethics
- Development of a framework for public health policies

Results

- Identified ethical issues were allocated to the following groups:

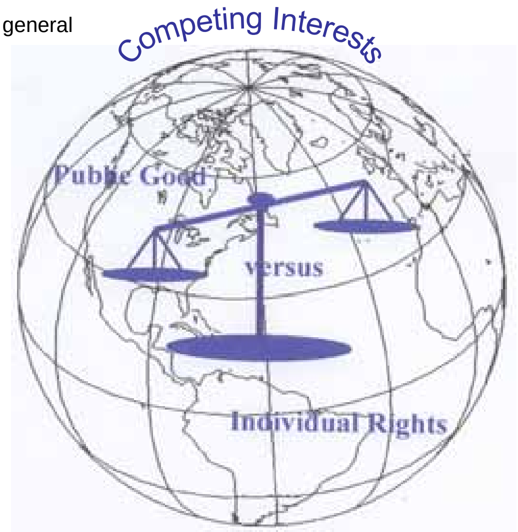


- Nine main ethical conflicts were identified.

  Ethical conflicts arose by applying public health measures like isolation and quarantine, surveillance and contact tracing, travel restrictions or global information sharing.

Clinical Ethics

- Duty of health care workers (HCWs) to care for patients versus
  - duty to care for themselves to minimize the risk of transmitting disease to others
  - duty of health care institutions to maximize the safety of HCWs
  - equality between HCWs during an epidemic
- Duty of physicians to act in the best interest of individual patients versus
  - physician’s responsibility to the public rather than to the individual patients in emergencies
- Priority setting in health care institutions (collateral damage) versus
  - equity



Public Health Ethics

- Common good of public health versus
  - individual liberties
- Information public need for containing the spread of disease versus
  - privacy and confidentiality of information

Global Health Ethics

- Global solidarity versus
  - suppressing health care information with global interests
  - intellectual property rights

Conclusion

- Traditionally the study of infectious diseases has focused on scientific and medical issues. Ethical issues are less considered
- New situation: First time after decades confronted with a rapidly spreading respiratory disease with pandemic potential
- SARS had a great impact on social order and economic growth
- SARS and health care workers identified as major ethical issue! What level of risk can be accepted for HCWs?
- Essential need for communication, transparency and education to improve compliance and to reduce stigmatization
- Various social and political contexts will be a challenge for globally accepted ethical guidelines
- How to strike a balance between public’s health and individual rights to privacy, liberty, and freedom of movement?

Key message

- **‘SARS – like’ diseases need quick responses**
- **Public health policies need ethical fundaments for adequate decisions**
- **Principles of biomedical ethics have to be transformed to collective level**
- **Individual and collective interests have to be matched**
- **Autonomy of the patient – Autonomy of citizens**
- **Beneficence for the individual – Beneficence for populations**
- **Nonmaleficence towards individuals – Protecting societies**
- **Justice – Equity**

6.2 Certificate of Originality

I hereby certify that the diploma thesis I am submitting is fully and completely original to me and that neither copied, improperly used, nor otherwise violated any rights of any third party in preparing and submitting the diploma thesis and that it was not a partially or in whole written, revised or substantially edited by anyone other than me.

……………………………………….

Sabine Schipf

Stade, 6th December 2006

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