CHAPTER 19: CONCLUDING REFLECTIONS

What lessons can we learn from the legislative response to the AIDS epidemic? This is an important question considering that new, deadly diseases may in the future again appear on the world scene. The research in this book examines why and how legislatures have responded to the AIDS epidemic. Insight into the historical context of legislative responses to AIDS should, to a certain degree, help us to predict and understand the legislative responses to future epidemics.

The original objective of the book was to try to assess the effectiveness of legal instruments adopted in jurisdictions around the world. This objective could not be attained due to the limitations of the available data, which made serious analysis impossible. For example: information on the implementation of legislation is necessary if one is to assess its effectiveness, but such information was rarely available. It was therefore decided to refocus the research on the question how and why legislatures have responded as they did.

The book aims to make a contribution to the literature on comparative public health law, a field which is gaining more and more importance due to international developments such as the collaboration and harmonization in the legal field within the European Union. The results of the research described in this book have both theoretical and practical implications. On a theoretical level, the book gives a descriptive and analytical categorization of possible legislative reactions to a major public health crisis. It also takes initial steps towards explaining legislative responses. On a practical level, it invites public health policy makers to learn from one another by giving an overview of various options chosen by different legislatures.

For a number of reasons, only tentative conclusions can be drawn from the available data. First, the legal field concerned with AIDS has been changing very rapidly. The conclusions of this book, formulated at the end of each part, are, therefore, limited to the 10-year period under study. Second, the analysis is based only on jurisdictions which made their data available (either directly or through WHO), which may have influenced the conclusions. Third, the methods used to analyse the data are mostly indirect, which means that the data can do no more than strengthen or weaken the plausibility of the formulated hypotheses.

Following an introduction to AIDS and the legal responses to the AIDS epidemic in Part I, Part II examines the possible influence of the societal reaction to the epidemic on the reaction of the legislatures. Based on an analysis of societal reactions to epidemics in general, three stages of societal reaction are defined:

- denial that the epidemic is occurring within the given society;
- recognition that the epidemic is present;
- mobilization against the further spread of the epidemic.

It is shown that this (presumed) pattern of societal reaction is as expected reflected in the worldwide pattern of legislative response. As the theory on the relationship between public opinion and legislative change predicts, legislatures seem, on the whole, to have followed the development of the societal reaction to the AIDS epidemic.

This developmental sequence seems to entail that public authorities are first inclined to a non-reaction or to measures intended to keep AIDS out of the jurisdiction (which corresponds to the denial stage of the societal reaction). Thereafter follows the phase of societal recognition and legal instruments connected with obtaining epidemiological information on the epidemic. Finally, the mobilization stage of the societal reaction is reflected in legal instruments adopting prevention/treatment programmes to prevent the further spread of AIDS.

What remains unexplained is the speed with which the three stages follow each other in time. For instance, why have some jurisdictions completed all three stages whilst others are still in the stage of denial? Asian, African and Eastern European jurisdictions have generally reacted more slowly than Western countries. Has the reaction been delayed because of political considerations? Did the epidemic start later (this is definitely not the case for Africa)? Another possibility is that the societal reaction took longer to develop or to influence the legislature.

In Part III, the relationship between the medical profession and the legislature is studied. The objective of this part is to examine whether the medical profession has influenced legislatures in their reaction to the AIDS epidemic. Four subjects are examined in detail:

- the protection of health care workers;
- informing other health care workers of the seropositive status of a patient;
- the duty to care for seropositive patients and people with AIDS; and
- the problems surrounding seropositive health care workers.

The question whether the medical profession influenced legislatures in their reaction to AIDS cannot be answered with any assurance due to the limited data available. The data does show that the medical profession and the legislature approached the social problems posed by AIDS in a similar way. Nor did the AIDS epidemic change the basic relationship between medical associations and legislatures: medical assocations generally adopted measures earlier than legislatures, and these were more detailed than the legislative instruments. Legislatures appear to be reluctant to adopt legal instruments on medical matters, especially when the subject to be regulated is ethically, technically or otherwise controversial. In effect, legislatures leave a wide discretion to the medical profession, stepping in only when needed to protect interests the profession seems to be according too little weight.

In Part IV, the contents of the legislative reaction are examined in more detail. Three models were formulated as a basis for a systematic analysis of the legislative response:

- the voluntary model based on individual responsibility to prevent the further spread of AIDS;
- the administrative control model, where the public health authorities have the primary responsibility to protect public health; and
- the compromise model, which combines individual responsibility with the duty of public authorities to protect public health.

The research covered four main subjects:

- testing for the presence of HIV antibodies;
- reporting of HIV, AIDS and related symptoms;
- contact-tracing and partner-notification; and
- isolation.

In general, the primary concern of legislatures has been the reporting of AIDS, which in most cases is made mandatory and nominal (administrative control model). That such a large number of jurisdictions have adopted reporting legislation should be seen in connection with the fact that nearly half of the jurisdictions examined are still in the recognition phase (see Part II). The prediction in Part II that legal instruments on reporting will be a first priority for legislatures is strengthened by the data in Part IV.

The second concern is the protection of the human tissue supply, which is usually dealt with by adopting routine testing of donors or donated tissues (voluntary model). If legislation on isolation and contact-tracing is adopted (which is only the case in a few jurisdictions), behaviour-based isolation and patient-referral with a contingent possibility for the physician or public health authority to intervene, are preferred over other methods (compromise model). The fact that such a small number of jurisdictions have adopted legal instruments on contact-tracing and isolation may be explained by the assumption that legislatures are reluctant to adopt measures on controversial ethical and technical issues.

Concerning the use of the three models, the data shows that legislatures do not opt for one model throughout the legislative response, but select a model for each specific measure based on its importance for the prevention of the further spread of AIDS, its impact on human rights, its presumed effectiveness, etc.

Although the study was limited to a comparison of the contents of legislative activity, something can be said about legislative preferences concerning the various subjects on which legal instruments were adopted. An analysis of these legislative preferences provides an indirect assessment of legislative effectiveness. The data shows that reporting programmes and testing programmes for human tissue supply have been widely adopted, and it can therefore be assumed that these measures are seen as an effective means of preventing the spread of AIDS. Regarding isolation and contact-tracing, no consensus can be found in the literature and only a few jurisdictions have adopted legal instruments implementing such programmes specifically for AIDS, which possibly indicates an unfavourable cost-effectiveness ratio of such measures. More solid information on the effectiveness of various legislative approaches is necessary to make any firm conclusions.

Throughout the book, legislatures are seen as searching to balance the protection of public health and the protection of the individual. On the one hand, effective measures must be adopted to prevent the epidemic from spreading in the population and, on the other hand, authorities must ensure that the human rights of every indiviual, as reflected in numerous international declarations and conventions, are protected. Even though restrictions on human rights can be acceptable in certain situations, for instance when the public health of a jurisdiction is endangered or the life of an identifable person is put at risk, public authorities must always take human rights into account.

In the case of AIDS, this search for a balance is a prominent theme. AIDS is a disease which is spread through highly personal behaviour (sexual relations, injecting drug use). The individual aspect of AIDS and the protection of individual rights have thus commanded specific attention. At the same time, if the epidemic is to be controlled, this very individual behaviour needs to be effectively regulated, which may require oppressive, intrusive and expensive measures. Looking at the contents of the legislative response (cf. Part IV), this

search for a balance can be clearly seen. The more restrictive the measure (e.g. isolation), the fewer the legislatures which adopt it and the more the legislatures try to use the compromise model instead of the administrative control model (e.g. behaviour-based isolation instead of disease-based isolation). For each legislature, this balance will be struck differently. The result, as Kirby (1987) observes, is that "law is local".

The search for balance may explain that the influence of society in the denial stage of the epidemic (cf. Part II) is mainly reflected in non-reaction by legislatures. Only a few examples could be found where legislatures adopted specific measures appropriate to the denial stage (e.g. testing all incoming persons (foreigners and/or returning nationals) to keep AIDS out of the country). By not reacting in the denial stage, legislatures avoid adopting restrictive measures that do not take into account the individual aspect of the disease.

In the medical fields examined, legislatures have likewise adopted the role of a 'hesitant balance-seeker' in their relation with the medical profession (cf. Part III). Even though legislatures are reluctant to adopt legal instruments in this delicate, technical and ethically controversial area, leaving the adoption of recommendations to the medical profession, they do have a control function in balancing the protection of health care workers and individual rights of patients (e.g. if the medical profession proposes to test all patients).

AIDS EN REGELG
DE ACTIVITEITEN
SAMENVATTING

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Deel I: Inleiding

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