

Chapter 9

The Impact of AIDS on the Dutch Health Care System

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The AIDS epidemic, like any other epidemic, is not only a medical but also a social phenomenon. Medically, AIDS is a fatal disease which predominantly affects relatively young people. Regardless of the quantitative size of the epidemic, for the individuals infected and affected, AIDS is qualitatively a big problem, since their lives are disrupted by it. But numbers only identify the first and most obvious impact of the HIV/AIDS epidemic: the population of infected, sick and dying persons. Behind the statistics lies the biographical disruption of each individual who is infected. But the diagnosis of HIV or AIDS affects not only the person who is infected or ill, it also changes the life of people in his or her immediate and intimate environment. And beyond the individual and his immediate environment are the variety of institutions and practices that may also have been affected by the epidemic. Last but not least, epidemics may induce uncertainty, fear, blame and flight in those who are not (as yet) infected, and those who think that those who are infected pose a risk to them (Camus, 1947; McNeill, 1976).

At this point in the history of the epidemic, we may conclude that AIDS is still a quantitatively small problem, at least in the Netherlands with a population of 15 million. However, when the first cases of AIDS occurred in 1982, no one had any idea of its prevalence and incidence. The implication of this was that in the early years of the epidemic, decision making took place in an extremely uncertain situation. Because the earliest predictions of future incidence and prevalence generated very high estimates with very large confidence intervals, they were of limited use. Should one plan for the worst case or for the best case scenario, or for somewhere in between? Later on these early calculations were proven to be far too pessimistic.

In this chapter we will describe how the health care system has responded to the threat of AIDS in such a highly uncertain decision making situation, and try to analyze what the impact of HIV and AIDS has been on health care policy and the health care system. In particular, we will focus on the impact of AIDS on formal and informal health care provision, and on public health policies and practices. The impact of AIDS on the health care system cannot be understood if the baseline situation is not taken into account. By the baseline situation we are referring to the configuration of health and social services before AIDS first appeared. Evaluating the impact of

AIDS requires an assessment of principles, policies and practices prior to its appearance.

Before AIDS, countries differed dramatically with respect to health care organization, public health policies, patient rights, human rights, sex education and health promotion, attitudes towards drug use, homosexuality, prostitution, and so on. Prevailing principles, policies and practices have to a great extent influenced both the kinds of initiatives societies have taken, and those they have refused to take in the fight against AIDS. For example, in most of the countries where needle and syringe programmes are in place today, these programmes were only introduced because of AIDS. In the long term, therefore, AIDS may have an important effect on drug treatment systems and approaches in these countries. However, in countries where such programmes were already in place, the advent of AIDS may have had only an incremental effect. And the refusal of countries to begin with such programmes, despite all evidence of their effectiveness, is related to the fact that a harm reduction approach is believed not to fit with the prevailing principles and policies in the war against drugs. The impact of AIDS can therefore only be understood if the baseline situation is taken into account.

Principles of Dutch Health Care

Important characteristics of Dutch health care, public health, and health education policies and practices are an expression of deeply rooted moral and cultural principles. These principles include the following:

- The duty of all to help others when they are sick (the 'Samaritan' principle as Wulff (1995) calls it). If someone is in need of help, the moral norm is that help has to be provided. Today help is provided through a collectively-paid-for health care system. The fact that it is collectively paid for, reflects the principle of solidarity and its concomitant, the principle of distributive justice.
- The principle of self determination, which finds its expression in different areas such as the acceptance of free choice in relation to sexuality, as well as in medical decision making about the end of life (policy on the use of euthanasia and physician-assisted suicide). The principle of self-determination is closely linked to the fact that we live in a democratic society. We want to live our lives according to our own values and wishes while taking into account the freedom of others. This principle is closely linked to the belief in the ability of citizens to make rational and responsible decisions with respect to their health. For example the Dutch vaccination programme is executed on a voluntary basis with almost 95 per cent of the population participating. It implies an appeal to personal responsibility, a faith in the persuasive power of education and dialogue, and belief in the

integrative capacity of a society where there is a strongly developed sense of solidarity and mutual trust (Schnabel, 1989; Hofstede, 1991; Fukuyama, 1995).

- The principles of liberal pragmatism and non-moralistic pragmatism. The Netherlands is a liberal country. Citizens have the right to live their lives according to their own norms and beliefs within a legally and morally defined context. However, if there is a tension between law and public health, or between law and the principle of self-determination, a pragmatic and non-legalistic approach is often adopted. One of the best-known examples of this can be found in the harm reduction approach in the area of drug use (prosecute the traders, not the users), and the public health approach to sex work. Neither drug use nor prostitution is legal, but both are tolerated (in Dutch a new word to describe such a policy of repressive tolerance has emerged: *gedoogbeleid*), because it is believed that forbidding these practices will make the problem uncontrollable. The result is that groups and individuals already at the margin of society will go underground. It is believed that this should be prevented as much as possible.
- The principle of integration and participation: It is felt essential that all citizens should be able, and be enabled, to participate in society as much and for as long as possible. The integration of people with different backgrounds – in terms of religion, race, political orientation, gender – is promoted. Segregation should be prevented as much as possible. This principle is especially important since it also applies to marginalized and vulnerable groups. It is felt important to stay in touch as much as possible with vulnerable groups of people and patient groups, by establishing clear lines of communication between policy and political levels and ‘vulnerable’ groups and their advocates. Control is believed to be less effective if it takes the form of supervision and repression. Control in the shape of social control and self-control is believed to be more effective.
- Culture of consensus and commitment: decision making in the Netherlands aims at reaching consensus and obtaining commitment from all relevant parties. All relevant parties are involved in the decision making process in order to realize partnerships. In the area of health care, the Sick Fund Council exists where providers, financiers, patients, unions, employers, government and appointed independent experts meet and decide about what kind of services have to be reimbursed.

Policies and Practices at Baseline

The above principles are put to practice through political decision making and policy formulation and execution. The result of the principles of solidarity and distributive justice is an elaborate health care system which is available, accessible and affordable to all citizens as a result of obligatory health care insur-

ance for all. Health care insurance in turn is part of a well developed social security system, covering, among other things, unemployment, sickness leave and disability. From the conviction that services should be available to all followed a policy that promotes general institutions and discourages categorical health care services and organizations. This formal policy, however, has never completely excluded the possibility of financing categorical institutions, as can be illustrated by the existence of specific institutions in the areas of oncology, epilepsy and – in the early 1980s – haemophilia.¹ More relevant to the care of AIDS, categorical organizations existed in the areas of drug treatment and mental health care provision for homosexual men and women. An elaborate network of drug treatment services, such as methadone and other treatment programmes, and needle exchange programmes (started as a method of preventing hepatitis B transmission among drug users) was already in place before the first case of AIDS was detected. With respect to homosexual men and women, the Schorerstichting, a mental health service organization for gay men and women, was financed by government and health care insurance. In the area of primary health care and sexually transmitted diseases, the Ancillary Service Department (SAD) provided additional services for gay men.²

The Netherlands is often pictured as a liberal society, one concerned with an openness about sexuality and the acceptance of different sexual lifestyles. There is a high tolerance towards homosexuality among the Dutch population. Since the 1970s, we have had an open policy with respect to the prevention of unwanted pregnancy – condom use, contraceptives paid by health care insurance, and pregnancy termination (abortion). Again, there are multiple principles at play including the principle of self-determination and the belief that citizens are capable of making rational and responsible decisions for themselves and others, and the principle of non-moralistic pragmatism.

Early Planning for the Future: 1982–87

When the first case of AIDS was diagnosed in 1982, the initial response came from professionals of varying backgrounds (infectious diseases, public health, health education and health promotion, medicine, blood transfusion and blood products), and community organizations (especially gay advocacy groups and gay service delivery organizations, such as SAD and Schorerstichting, and haemophilia groups). These individuals and organizations came together because of their shared anxiety about a new disease, possibly caused by a virus that apparently could be transmitted sexually and through blood and blood products. Most of the people who met together were not strangers to each other. In the gay community, the rise of STDs in the 1970s had triggered the foundation of the SAD, and in 1979 a large study about the occurrence of sexually transmitted diseases among homosexual men in and around Amsterdam was conducted by the Amsterdam Municipal

Health Department (Coutinho, 1984). The advent of hepatitis B had earlier created problems with respect to the safety of the blood supply. As a result, the health inspectorate already had working contacts with groups of gay men (the Dutch Gay and Lesbian Association, NVIH COC), sex workers (Red Thread), drug users (Junkie Union), as well as with public health officials.

In many ways, therefore, the Netherlands had an advantage over many other countries because of existing arrangements, which included, among other things, an elaborate drug treatment system, gay specific services in Amsterdam – the epicentre of the epidemic – and open lines of communication with representatives of other risk groups. All of this facilitated a quick response.

Bloody Sunday

A crucial date in the Dutch history of AIDS is 30 January 1983, which became known as 'Bloody Sunday'. Present were representatives from the blood sector, the health inspectorate, public health, an association of people with haemophilia, physicians, health education and health promotion, and gay advocacy groups. Apart from the health inspectorate and a representative of the National Institute on Public Health, neither the Ministry of Health nor the government was present. This may be perceived as strange, but within the Dutch context it is quite normal. As long as the relevant actors in the field take responsibility, policy and politics keep a distance. And in the area of AIDS, the front-line organizations took their responsibility, as they had in the past.

Bloody Sunday was the date when AIDS was first acknowledged as a problem in the Netherlands. The meeting was concerned with the safety of the blood supply in general, and, more specifically, how to prevent people at risk of HIV infection from donating blood. The collective decision that gay men should refrain from donating blood voluntarily instead of mandatorily debarring them, is illustrative of Dutch policy. An appeal to personal responsibility fitted the belief in the ability of citizens to make rational decisions with respect to their own health and the health of others. Moreover, it fitted very well the culture of consensus and commitment:³ the decision taken was a common decision. In order to fight AIDS, collaboration and consensus became the key words. It was not gay men against physicians, not gay men against people with haemophilia, not a public health approach against a health education approach, but all should work together instead.

Self-organizing Capacity of Front-line Organizations

Bloody Sunday also marks the establishment of the National AIDS Policy Coordination Team, which was given responsibility for initiating and coordi-

nating the response to AIDS. Until 1987, the AIDS Coordination Team and the affiliated extended council (Breed Beraad), and the front-line organizations defined the desirable course of action.

The first ministerial memorandum on AIDS presented to Parliament by the Secretary of Health was made in September 1985. Apart from offering an overview on ways in which front-line organizations could be facilitated in doing their work, and apart from stressing the importance and effectiveness of the AIDS Coordination Team in terms of coordination and information provision, the memorandum laid the foundations for the features of AIDS policy as we know it in the Netherlands today. Since no treatment was available, since the virus apparently could not be transmitted through everyday contact, since contracting the virus supposedly caused AIDS only in a minority of cases (in 5 to 10 per cent of affected individuals, it was at that moment assumed), and since revealing one's serostatus might lead to stigmatization, it was decided that AIDS should not be a mandatory reportable disease. Instead, physicians were requested to report cases of AIDS on a voluntary and anonymous basis. Not being a reportable infectious disease, involuntary partner notification would not occur. Testing could only be performed with informed consent and if accompanied by pre- and post-test counselling. Emphasis was to be placed on information and education as the main means of prevention.

With respect to care and treatment, the general principle of Dutch health care policy, that wherever possible care should be provided by general service delivery organizations, became a cornerstone for AIDS policy. Categorical organizations were only financed if absolutely necessary. The application of this principle did not exclude AIDS specific approaches, but the challenge was to balance general principles and specific needs.

AIDS: From a Specific to a General Problem

A second landmark in the Dutch history of AIDS is a 1986 meeting at the National Institute of Public Health where it was decided official policy should not be limited to 'high risk groups' but to the population as a whole. An information campaign was to be started, and the AIDS Coordination Team was transformed into the National Committee on AIDS Control (NCAB), to be established by the Ministry of Health and having the status of an official advisory body to government. The decision that AIDS should no longer be treated as a specific problem of gay men and other risk groups, but as a general problem, was not taken overnight. But there was consensus over the final decision, probably because the reconceptualization was a win-win situation for all the parties involved. From the start, gay men had emphasized that behaviourally homosexual men happened simply to be the first to be affected, and that they could not be seen as responsible for spreading the virus. AIDS might be a big problem for gay men, but that did not make it a gay disease. AIDS could very easily become a general problem. The population as a whole

therefore needed to be addressed. AIDS should be considered a threat to every individual's health and sexuality.

The Period between 1987 and 1991

In 1987, the first policy document on AIDS was presented to parliament. This document described an integrated policy on AIDS involving:

- the implementation of an effective education and prevention programme;
- the development of an optimal AIDS care infrastructure;
- the stimulation of AIDS research, covering the basic sciences, clinical sciences, epidemiology, and the social and behavioural sciences;
- the monitoring of legal and ethical issues; and
- the prevention of discrimination and stigmatization towards people with HIV and AIDS.

An important means of executing the proposed policy was the NCAB, the successor of the AIDS Coordination Team. In terms of composition and working methods, the NCAB looked like other advisory bodies to government. All the stakeholding parties met in closed session to reach consensus on policy issues. On a regional level, Regional AIDS Platforms played an analogous role with respect to the organizations responsible for the execution of AIDS policy. It is accepted that all stakeholders carry with them specific interests and objectives, but it is believed that in the end specific interests will be made subordinate to collective interests and one common mission: the fight against AIDS. But there were differences with other advisory bodies as well. First, the NCAB focused on one disease, and operated next to general advisory bodies such as the National Health Council. Second, compared to other advisory bodies, patient organizations and community groups played a more prominent role.

The Normalization of AIDS

With the acceptance of the 1987 Policy Document on AIDS, the normalization of AIDS became an explicit aim of Dutch AIDS policy.⁴ This was not as an expression of resignation, but as a strategy for adaptation to and control of a potentially large problem. Moreover, it was felt that normalization would divert attention from vulnerable groups, and therefore decrease the chance of discrimination and stigmatization. In this way normalization may be seen as part of the tradition of liberal pragmatism. Trust in personal and mutual responsibility can only be maintained as a starting point for policy when citizens have a sense of personal responsibility and trust is valued by the citizens. Normalization also explains why it turned out to be relatively easy to

make AIDS policy, AIDS prevention, AIDS care and the fight against AIDS, a joint effort involving the state, science, health care, social services, education, people with HIV and AIDS, their advocacy groups and their solicitors.

The down-side of the normalization, however, was that the influence of gay advocacy groups and gay service organizations decreased, while the influence of patient organizations and general service organizations increased.

The Planning of Health Care Provision

From 1987 onwards, there was systematic attention to the planning, organization, and content of care and treatment. The challenge was to plan for the future while the decision making situation still was uncertain. Theoretical calculations did not exclude the possibility of an epidemic of considerable size. The risk could not be limited to relatively small groups at high risk, but had to be considered and responded to as a potential problem to all. This presupposition had a dramatic impact on ideas about the planning of health care services. If AIDS was to become a general problem of considerable size, then it did not make sense to invest heavily in categorical organizations. From 1987 onwards the planning of health care therefore became embedded within the existing configuration and became subject to prevailing principles.

The starting point for the planning and organization of AIDS care was the belief that AIDS-related problems could and should be dealt with within the existing health and social services policy framework and organizational network. Only if general policies, rules, regulations, and treatment and care facilities turned out to be ineffective and inefficient, was the possibility of categorical AIDS treatment facilities to be considered. A second starting point was the conviction that every Dutch citizen that was or might become HIV-infected, in whatever part of the country, should receive high quality care. This decision was made on the basis of distributive justice, but also on the hypothesis that AIDS might become a problem that was more or less evenly distributed over the country.

Consequences of this policy choice included efforts to inform and train everyone working in the health care system, and the expectation that every hospital and all hospital staff would treat and care for people with HIV and AIDS. This expectation applied to nursing home care as well. In order to prepare for a significant number of patients needing nursing home care, additional financial resources were allocated to 29 nursing homes across the country. Similarly, the financing of volunteer programmes was not so much guided by the number of people with AIDS in a region, but by the expected number of people with HIV. By 1990 more than 30 volunteer programmes were spread over the country. By 1990 a structure had been created that could have dealt with a larger number of, and more widely spread, AIDS cases than were actually to transpire.

In a later stage 11 hospitals across the country were designated core

hospitals, with the Academic Medical Centre in Amsterdam as national reference hospital. Important tasks of the core hospitals were the execution of clinical trials, the dissemination of information, the formulation of protocols and standards of care in the biomedical field as well as in nursing and psychosocial care. The policy principle that all hospitals should be willing to provide care did not exclude the possibility of AIDS specific approaches, treatment units, AIDS reference hospitals, AIDS specialists, AIDS nurses and AIDS consultative nurses; it merely meant that specific *services* should be part of the more general structures.

With respect to categorical service *organizations*, discussions were more problematic. With respect to the drug treatment system, it was acknowledged that these organizations played an essential role in the prevention of HIV. They executed the needle exchange programmes, they were in contact with drug users, and they knew in what language drug users should be addressed. However, HIV/AIDS treatment and care were to be provided by the general system. With respect to gay men, an analogous set of issues arose. Policy makers, financiers, and a majority within the NCAB discouraged the creation of gay specific AIDS services. From 1987 onwards gay specific services and advocacy groups were given primarily the task of executing policies, while their influence on the design of policies decreased. Operational tasks were not given to them with the objective to keep gay specific services and activities intact. Instead such organizations were seen as an important reservoir of knowledge and expertise that could be disseminated throughout the general health care system and public health services.

Getting Realistic: 1991 to 1995

In the early 1990s, an increasing number of factors suggested that AIDS might become a more limited health care problem than had hitherto been supposed, in terms of both size as well as costs. The Dutch scenario study (STG, 1992) prepared the grounds for a revision of AIDS policy.⁵ Important conclusions from the scenario study included:

- AIDS will create a substantial but by no means insurmountable problem for the health care system;
- HIV has not become widespread outside the known risk groups; and
- the chances of a widespread epidemic among the heterosexual population are slight.

It was not concluded, however, that continued efforts for prevention were not needed. On the contrary, there is a continued need for AIDS education and prevention. Indeed, explicit information and education programmes have contributed to a containment of the HIV epidemic. To not continue with educational efforts might be seen as a signal that AIDS is no longer a threat to public

and individual health, and might therefore have a negative effect on sustaining safe behaviours. The scenario report warned policy makers not to fall into the 'paradox of prevention' trap: effective prevention contributes to a containment of problems. By taking away the means of containment, the problem may in fact increase.

The revision of official AIDS policy did not occur overnight, but happened only after confirmation and the downward adjustment of calculations and epidemiological extrapolations based on the scenario study. Data from the HIV surveillance system and the AIDS reporting system made clear that the spread of HIV had indeed been limited. New infections among the heterosexual population had stayed well below 1 per cent (as measured through the HIV monitoring system), and most of these infections occurred amongst women and men coming from endemic areas. The prevalence of HIV among injecting drug users outside Amsterdam had stayed well below the Amsterdam percentage (20–25 per cent). And the steepness of the curve with respect to new infections among younger gay and bisexual men had decreased. Infections were still occurring, as well as risk behaviour, but not at any rate characteristic of gay and bisexual men in older age groups. Moreover, it had become clear that AIDS was a geographically focused problem with Amsterdam as its core, and that the AIDS and HIV epidemic was increasingly linked with lower socio-economic status. Last but not least, despite the fact that the percentage of gay men on the total number of AIDS diagnoses had decreased from 89 per cent in the period 1982–85 to 72 per cent in 1996, AIDS continued to be a serious problem for gay men.

It was against this background that the NCAB published its final advice in September 1995. Core elements of this were:

- Planning of services should be made more dependent on epidemiological data. This resulted in the advice to reduce the number of core hospitals and nursing homes.
- Services should take into account the different needs of different groups. A more supportive attitude towards categorical services for gay and bisexual men and women, and drug users was expressed.
- Continuation of support of volunteer care, taking into account the differential burden on the formal and informal care systems, and the different needs in different groups. At the same time, the planning of buddy projects should be made more dependent on epidemiological data. In a substantial number of regions, the number of volunteers exceeded the number of people with AIDS. Some volunteer programmes had stopped because there was a lack of patients in their catchment areas, and others had merged in order to improve efficiency. By 1996 the number of volunteer programmes had decreased from over 30 to 23.
- Continued provision of adequate psycho-social support, as provided by care givers with a double expertise, and by community mental health services.
- Continued attention to the social participation of people with HIV/AIDS.

This was considered all the more necessary, because of recent social policy changes. For example, the cost of the first 52 weeks of illness had become the responsibility of the employer, making selection on the basis of health more important. The conditions of the Disability Act had also become stricter and financially less favourable.

- Reaffirmation of patient organizations as key stakeholding parties and as an accumulated source of experience and expertise. Assigned tasks to patient organizations included 1) consolidation of advances in treatment and care, 2) ensuring that services and treatments – especially new therapies – stay or become available, accessible and affordable to all, 3) ensuring that proposed policy changes do not result in a curtailment of human and patient rights, 4) being an advocate for the optimal participation of PWHIV and PWAIDS in society and ensuring that selection on the basis of health status, access to the labour market and insurance becomes difficult or impossible, and 5) ensuring that preventive programmes and the resources they need remain available and accessible.

The bottom line of the advice was to preserve what is good, and invest in quality, efficiency and effectiveness. The policy recommendations have to be seen in the context of the then existing treatment possibilities, which were considered to be rather limited. AIDS was still very much seen as a fatal disease, and by implication much attention was paid to the quality of death.

New Drugs, New Hope, New Questions

Less than one year after the final NCAB report, the seemingly stable environment had changed dramatically. The XIth International Conference on AIDS (1996) in Vancouver was the first conference at which promising results were presented about new drugs, new combination therapies and new methods to determine viral load. The advent of protease inhibitors, it was felt, would have a compelling effect on AIDS care and prospects for people living with AIDS. These results gave rise to new hope. However, with the new drugs came new questions, not only for basic science and clinical science, but also for social science and behavioural research.

Compliance

New therapeutic regimens require considerable discipline on the part of the patient. He or she may have to take many different drugs, and he or she needs to take them regularly. From the literature we know that compliance is a major issue in patient treatment, and this is even more so in the case of AIDS. The drugs have quite serious side effects, and it is unknown what the side effects on the mid or longer term will be. Different drugs require different intake schedules (some on a full stomach, some on an empty stomach) – as a result life itself

becomes medicalized. A substantial number of people with AIDS belong to groups that have a poor record in terms of compliance (drug users, sex workers, psychiatric patients, homeless people). Since non-compliance is an important factor in drug resistance, the question has to be addressed how these people can be assisted effectively.

Quality of Life

Not much information is available on the impact of the new drugs and drug regimens on the quality of life. Although the few data that we have are not too disquieting, several questions have to be addressed. First of all it is unclear what are the size and seriousness of the problems that arise due to the intake of toxic drugs, especially if they need to be taken lifelong. Furthermore, combination therapies make the simultaneous use of some other drugs impossible; how will starting these therapies and stopping others affect morbidity and mortality due to other diseases? We know little about the mid-and long-term efficacy if people already have developed symptoms of AIDS – is it a one-time chance? What will the individual psychological effect be if the drugs do not work? Finally, many people to a certain extent had adapted to the idea that they were going to die in the reasonably near future. Their perspective has suddenly changed. One cannot assume automatically that people will perceive this change as positive. What is a life without all the lost friends and a diminished social network, without a job, and having to live on a small income?

What Kind of Care?

The availability of new combination therapies will also have an impact on where treatment is going to be provided. Given the numerous combinations of therapy possible, and the complexity of viral load determinations, the role of physicians working in the core hospitals will most probably increase, and the role of GPs and home care will be limited to the final stages of disease. However, from the point of view of monitoring and compliance, the GP's office might be the better place, especially in Amsterdam where about 10 offices provide for 80 per cent of the total caseload. The work of volunteers will change as well, although it cannot be said what directions these changes will take. Is it possible, for example, to envisage volunteering for a period of 8 or 10 years? Will those who are infected but well, appreciate that kind of effort?

Who is going to pay?

At a more general policy level, the availability of new treatments requires decisions about the accessibility and affordability of these drugs. This will

occur in the context of more general policies with respect to the reimbursement of drug treatments and increasing pressure on the health care budget. Thus far, the swiftness of decision making has been remarkable. By July 1996, finances for the new therapies were made available. This was the result of the network that has been established for the last 10 to 15 years, though the decision was taken under and after an influential alliance between the AIDS Fund and Patients Organization (HIV Society).

In summary, what seemed to be a rather predictable policy environment in 1995 had become more turbulent by 1996, especially in relation to health care. New combination therapies have already led to new questions and changing problems and needs. Their advent will require new responses from all parts of the health care system: hospitals, home care services, mental health care agencies, volunteer organizations, public health agencies and health education agencies.

So what is New?

The question arises, is there anything new in AIDS health care policy? After all, almost every kind of service is embedded in the already existing structures, and similar initiatives to these in the area of AIDS can be found in other areas (cancer, epilepsy). In an early interim evaluation, Schnabel (1989) characterized Dutch AIDS policy first and foremost as typically Dutch, and second as a specific AIDS policy. General principles and policies were applied and turned out to be applicable to the problems that AIDS created. We believe that this conclusion still stands at the level of principles and strategic health care planning. However, if we look at tactical and operational planning and practices, AIDS has had an influence that goes even beyond AIDS care. We will illustrate this by looking at practices and policies in community involvement, the influence of patient organizations, patient involvement in medical decision making, the health promotion approach to STDs and HIV testing policy, and psycho-social care.

Volunteer Care

AIDS affected the gay population first and hardest. Even now, more than 70 per cent of people with AIDS in the Netherlands are behaviourally homosexual men. Throughout the 1980s, gay men, gay organizations and gay advocacy groups were a powerful driving force behind the creation of AIDS policy, and had a decisive influence on the content of that policy. Simultaneously, they executed prevention campaigns and provided services, of which the so-called Buddy Programmes are one of the most striking examples. In the Netherlands, volunteer care and community involvement are most visible, innovative and effective in the gay population. The first Buddy Programme was introduced in

1985 by the Schorerstichting; it was inspired by the San Francisco Shanti Project and the New York Gay Men's Health Crisis' mutual support programmes (De Rijk and Van den Boom, 1989). It was striking, because there are no cities in the Netherlands where the same kind of gay neighbourhoods can be found as in San Francisco or New York. Gay men form part of a rather loose network. Nevertheless, AIDS triggered a community or more precisely a latent network response. Volunteer help served two purposes: first, by providing social, emotional and practical support to fellow homosexual men; second, it helped gay men come to terms with the epidemic. It is illustrative of collective behaviour in a period of social change, where gay men from a mixture of solidarity and personal involvement gave shape to an innovative form of psycho-social support. The programmes turned out to be so successful in terms of providing support that there was a wish to expand the concept to other groups, notably drug users, ethnic minorities and heterosexual men and women.⁶

Although specific programmes have been organized, it remains a question if volunteer care will have the same benefits to, and basis in, other populations. Driessen *et al.* (1991) have pointed to the problems that volunteer care in a drug using population can face. One of the main problems is the absence of a common social denominator other than drug use. A somewhat similar problem is described for the very heterogeneous group of women with HIV (Te Vaarwerk and Gaal, 1995).

The impact of the Buddy Programmes goes beyond AIDS care. In the early 1990s, at a policy level it was acknowledged that an extension of this model might also be applicable to other diseases. In practice, however, the application of the model has progressed slowly, and much will depend on the efforts of large volunteer organizations, such as the Netherlands Red Cross.

The Influence of Patient Organizations

From the 1970s onward, there has been increasing attention on the disequilibrium between patient and health service provider, at both individual and institutional levels. Laws and regulations to strengthen the position of patient organizations and empower patients have been enacted.⁷ From this perspective, AIDS activists jumped on an already running train. But, although attention on the patient as a stakeholder within the health care system had been increasing, patient organizations did not meet on equal terms with other stakeholders (providers, financiers, government) in the mid 1980s. People with HIV and AIDS are prototypical for what De Swaan, Van Gelderen and Kense (1979) call 'proto-professionalized' patients, who wanted to be involved in decision making, including medical decision making, and had the knowledge and 'courage' to demand this right. PWAs challenged politicians, policy makers, public health officials, care givers and researchers since, generally speaking, they were well informed about the disease and its progression, the

available drugs and the drugs under investigation, and their rights and obligations. Moreover, they organized a global information network, so that information was transferred very quickly from one part of the world to the other. There was and there still is a fast and intensive exchange of information, expertise, and experience. AIDS reinforced and accelerated changes already latent within the institutions and within policy making. AIDS patient organizations were among the first to negotiate about, and participate in, decision making with respect to research policy and execution, service quality, the financing of treatments and organizing new modalities of care.

It is salient that physicians and other care givers, researchers, policy makers and other health care professionals have perceived themselves more as partners of patients and patient groups than as opponents. There was a real willingness to enter discussion and dialogue. This dialogue was initially organized within the context of the NCAB, the regional AIDS Platforms and National AIDS Trial Evaluation Centre (NATEC). The role of the Ministry of Health in the positioning of the patient organizations should not, however, be underestimated. Progressive policy makers utilized the momentum created by AIDS activism to increase the role of the patient in the triad: patient, provider and financier. In the 1990s, the influence of patient organizations has increased on almost every aspect of health care policy.

Patient Involvement in Medical Decision Making

In line with principles of self-determination and personal autonomy, patients perceived their role as stakeholders and partners in decision making as one that was not limited to general decision making in the areas of care and treatment, education and prevention. They also wanted to be involved in decision making with respect to starting treatments, refusing treatments and the active termination of life. Increasingly, PWAs became involved in medical decision making. Informed consent procedures with respect to starting new treatments are now the rule rather than the exception, and many hospitals have formulated policy with respect to the drawing up of living wills. But the most salient expression of their involvement in medical decision making is the fact that almost 50 per cent of PWAs discuss the possibility of euthanasia and approximately 25 per cent now die after the administration of euthanasia and physician-assisted suicide (Van den Boom, 1995; Laane, 1995; Bindels *et al.*, 1996).⁸

The above does not imply that doctors simply do what patients demand. For example, treatments outside regular Western medicine have not been integrated into the health care system; and euthanasia is only performed if the necessary requirements are met. Self-determination has not become the only leading principle. Care givers in the area of AIDS and patients alike have been trying to find a balance between the Samaritan principle (implying the duty to help) and the principle of self-determination (Wulff, 1995).

A Health Promotion Approach to STDs

The HIV test, which became widely available in 1985, opened unknown possibilities for containment of the epidemic. By testing, people could be identified; by notifying them, transmission to others might be prevented. The darker side of identification, however, is the possibility of marginalization, exclusion, and isolation. This in itself is not unique to AIDS, but AIDS became special as an early test case of the relation between constitutionally given rights on the integrity of the human body and the right to the protection of personal privacy on the one hand, and the constitutionally given responsibility of the state to protect and promote public health on the other. The wish to protect the population against further HIV transmission had to be balanced against principles such as informed consent and autonomous choice, the protection of personal privacy, the integrity of the human body, and the confidentiality of medical information.

Whereas in other countries, especially the United States, initial resistance towards HIV testing and screening was very much linked to the fear that testing and screening might jeopardize the still unstable emancipation of gay men, this argument has never played a significant role in the Netherlands. Gay advocacy groups in alliance with leading Dutch experts on health law and health ethics, successfully defended the position that testing and screening were acceptable only after the informed consent of every individual was obtained: the result was that mandatory testing at an individual, let alone population level, was made impossible (with the exception of the screening and informing of blood and plasmapheresis donors). Other methods of containment that relied on community education and voluntary anonymous testing were advanced and accepted.

Although health education and promotion by means of mass media campaigns and school programmes were already used as a health policy strategy in the areas of smoking, drinking, and nutrition, health education and promotion did not occupy a central place in STD prevention. AIDS accelerated the adoption of such approaches and invited their intensive application to infectious diseases. Increasingly, AIDS prevention became the domain of representatives of health education and promotion, and became characterized by an approach and vision that had not played a significant role in the traditional, medical approaches to STD prevention thus far. Knowledge of the modes of transmission and the promotion of safe behaviours (sex, injecting drug use, universal precautions for health care personnel) became the byword in a prevention policy that was new both in the sense of approach and content.

Psycho-social Care

An integrated approach to health care, that is to say a policy that acknowledged that well-being and quality of life are the result of physical, psycho-

logical and social variables, was formulated and advocated in the mid 1980s, independent of HIV and AIDS. It was in the area of AIDS, however, where an integrated approach was not only formulated as one of the cornerstones of policy, but implemented as well. Attention to the psycho-social aspects thereby became an indissoluble and necessary component of quality care. It was in the area of AIDS that the gap between the conceptualization of disease as a bio-psycho-social problem and the practical implementation of this new approach to understanding disease was first bridged.

Conclusion

In assessing the impact of AIDS on the health care system, it is our conclusion that AIDS has not altered the *structure* of the institutions that we have discussed, but has had a significant impact on the *contents* of care and prevention. Organizational structure has not changed, partly because HIV remains a small epidemic in the Netherlands. Relatively few people are infected with HIV, and elaborate health care services were already available, accessible and affordable as a result of obligatory health care insurance. No structural budgetary problems have arisen, and the denial of treatment due to being uninsured has *de facto* been neither an issue, nor a problem. In economic terms, AIDS has never seriously challenged the health care system as a system (STG, 1992). Since most of the effects could be dealt with in the already existing system, there was no compelling force for fundamental change in the structure of health care provision. And in order to change social institutions as complex as the health care and public health systems, a truly compelling force is essential. Moreover, early in the epidemic it was stated that AIDS care in all its facets should be or become an integral part of the existing health care system. This did not exclude the possibility of AIDS specific approaches, treatment units, and so on; it merely meant that specific services should be part of the more general structures.

In addition to being a quantitatively small problem, AIDS is a socially and geographically concentrated problem. Many geographical areas and strata of the population remain virtually untouched by the epidemic and hopefully and probably never will be. With respect to those specific groups affected by the epidemic, in the majority of cases specialist services were already in existence.

Given the size and character of the epidemic, it is the more surprising that AIDS has had a significant impact on health policy and practices. Although organizational structures have largely stayed intact, the often indirect and subtle influences of AIDS on health care and health care providers should not be underestimated. AIDS has made a difference in the area of STD prevention practices, volunteer care, patient involvement, and appreciation of the psycho-social aspects of somatic disease. AIDS reinforced and accelerated changes already latent both institutionally and in relation to health policy: attention for psycho-social problems and care, self-help and mutual support, support for

patient organizations, and an emphasis on patient rights. The possibilities that were constitutionally and legally available, for example in the area of patient rights, were and are optimally used. An illustration of this is the financial compensation granted to HIV infected people with haemophilia. In 1995 the National Ombudsman decided that the demands of the National Haemophilic Patient Association were justified, and urged the government to arrange for compensation. By utilizing every possible legal instrument, the patient movement had finally realized what they had fought for for more than ten years. Some responses have acted as catalysts for similar responses in other areas of medicine. In many ways, therefore, AIDS policy became an experimental garden for health policy.

The many things that have been realized in the area of AIDS in a relatively short period of time cannot be ascribed to one single actor. The successes seem to be more the result of a complex interplay between many different forces entering into alliances. AIDS policy as we know it today, is the result of what one might describe as a pioneering network organization. The motor behind this organization in many cases have been people with AIDS themselves, their organizations and their advocates. This is not to say that there has not been an absence of conflict of interest, and sometimes heated discussions, but they have rarely resulted in schisms. Within this internal arena people were gathered who knew the ins and outs of the traditional policy cycle as well as policy making in the area of health care and public health. Their actions were aided by good links with key professionals, policy makers, and politicians.

Innovation and the Principle of Parsimony

Flexibility is needed now that with the introduction of combination therapies the environment has become dynamic once again. A dynamic environment requires new ideas and room for innovation as well as openness on the part of professional and institutional groups to discuss their own roles, futures and *raisons d'être*. The present and the future demand room for experimentation and innovation. But will there be room for innovation and experiments in the years to come?

The space for innovation is not automatically available. Due mainly to the small size of the epidemic, negotiations about financial resources will take place within stricter budgetary constraints. This will make less room for manoeuvre, as well as force innovation outside of the regular health care system. Advocacy groups, researchers, and care givers alike will be confronted increasingly with the third principle distinguished by Wulff: the principle of acknowledging that the health care budget is limited and henceforth requires parsimony.⁹ The fight over a limited health care budget may become more fierce, since earlier configurations of 'consensus and commitment' have changed. Since late 1995, an NCAB has not existed. Its former tasks were

transferred to the Dutch AIDS Fund, the National Institute on Alcohol and Drugs (NIAD), and the Foundation for STD Control. The AIDS policy unit at the Ministry of Health has virtually disappeared. The PccAo has become embedded within the Dutch Foundation for Scientific Research (NWO) with a link to the AIDS Fund. Dispersion of influence may make it more difficult to develop consensus on future policy and practice with respect to AIDS care.

Last but not least, there is an internal issue to confront. Peter Drucker (1973) once described the difficult transition from pioneering to established organizations. It is true that as an organization grows, it cannot survive without adequate control and coordination. However, as soon as such mechanisms are implemented, the danger of dysfunctional bureaucratization arises. Instead of focusing on developments around themselves, organizations start focusing on internal processes and procedures and on self-preservation. Preventing this happening will be one of the most important challenges to all organizations involved in the fight against AIDS.

Notes

- 1 A general institution is accessible for every citizen who is in need of one of the services provided. A categorical institution is only accessible for people with a specific characteristic, for example a mental handicap, epilepsy, or belonging to a specific group (for example homosexual men and women, religious denomination). The Netherlands has a network of community mental health centers, which are financed through health care insurance. If a community mental health centre is founded that operates on a Christian basis, the rule is that this centre will not be financed out of public means, since such services are already provided.
- 2 The Schorerstichting is a mental health service organization for gay men and women; it was founded in 1967 and supported financially by government and health care insurance. The Ancillary Service Department (SAD) was founded in the early 1980s – before HIV and AIDS became a problem for the gay community – in order to deal more efficiently with the prevalence and incidence of sexually transmitted diseases in the gay population. Both foundations are located in Amsterdam. Recently the two foundations have merged into the SAD-Schorerstichting.
- 3 When the HIV test came available in 1985, the policy of voluntary non-donation stayed intact; but it was made clear to every donor that they would be informed about the test results. This policy of testing and informing everyone without the possibility of an individual opting not to receive the test result has been limited to the blood bank system.
- 4 On the premise that AIDS posed a threat to public health, and that the possible size of the epidemic might become substantial, AIDS was reconceptualized from a problem affecting small and distinguishable groups to a more general problem. General problems had to be dealt with

within the existing – normal – arrangements, even if the problem itself might have extraordinary characteristics. The adage was: deal with the extraordinary in as normal a way as possible.

- 5 In 1988, the Steering Committee on Future Health Scenarios (STG) asked the National Institute on Mental Health (NcGv) and the National Institute of Public Health and Environment (RIVM) to execute a scenario study in the area of AIDS. Prior to this study, scenario studies had been executed on cardiovascular disease, the elderly, cancer, chronic diseases, and on mental health. Scenario analysis first and foremost tries to incorporate representative data from different sources and process them into comprehensive and often new conceptual models. For an introduction in scenario analysis, the reader is referred to STG (1992); Jager and Van den Boom (1994); Van Genugten *et al.* (1996).
- 6 The National Haemophilic Patient Association has organized a mutual support programme for people with haemophilia.
- 7 For example, the 1983 change of the Constitution, adding to it the right of personal privacy and integrity of the human body. Several related laws have been passed including a law regulating the use of personal data; a law regulating the treatment contract between care giver and patient; and a law regulating the influence of patients or mentors on institutional functioning.
- 8 Again, it should be remembered that the issue of euthanasia has been discussed since the 1970s. In 1987, the Royal Academy of Medicine (KNMG) after a year-long discussion formulated criteria and general guidelines that had to be fulfilled in order to end the life of a patient by means of euthanasia and physician-assisted suicide.
- 9 The other two principles are: the Samaritan principle and the principle of self-determination.

References

- AIDS FONDS (1996) *Behandelingsmogelijkheden bij HIV/AIDS. Inventarisatie van Consequenties en Aanbevelingen*, Amsterdam: Stichting AIDS Fonds.
- BINDELS, P.J.E., KROL, A., VAN AMEIJDEN, E., MULDER-FOLKERTS, D.K.F., VAN DEN HOEK, A.R., VAN GRIENSVEN, G.P.J. and COUTINHO, R.A. (1996) 'Euthanasia and physician assisted suicide in homosexual men with AIDS', *Lancet*, **437**, pp. 499–504.
- VAN DEN BOOM, F. (1995) 'AIDS, euthanasia and grief', *AIDS Care*, **7**, Supplement 2, 19, S. pp. 175–86.
- VAN DEN BOOM, F., GREMMEN, T. and ROOZENBURG, H. (1991) *AIDS: Leven rond de Dood. Nabestaanden over Ziekte, Dood en Rouw*, Utrecht: NcGv.
- VAN DEN BOOM, F., JAGER, J.C., LUMEY, L.H. and RUITENBERG, E.J. (1990) 'Het wetenschappelijk AIDS-onderzoek: randvoorwaarden van de onderzoeksprogrammering', in I. RAVENSLAG, M.A.M. DE WACHTER and

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- H.A.E. ZWART (Eds), *Aids. Instellingen, individu, samenleving*, Baarn: Ambo.
- CAMUS, A. (1947) *La Peste*, Paris: Editions Gallimard.
- COUTINHO, R.A. (1984) *Sexually Transmitted Diseases among Homosexual Men. Studies on Epidemiology and Prevention*, Doctoral Thesis, Amsterdam: Rodopi.
- DRIESSEN, A., VAN DE VELDEN, L., VAN DEN BOOM, F. and DERKS, J. (1991) *Steun van de Regenboog. Vrijwillige Hulpverlening aan Verslaafden met AIDS*, Utrecht: NcGv.
- DRUCKER, P. (1973) *Management: Tasks, Responsibilities and Practices*, New York: Harper & Row.
- FUKUYAMA, F. (1995) *Trust*, London: Hamish Hamilton.
- VAN GENUGTEN, M.L.L., RUTTEN, F.F.H. and JAGER, J.C. (1996) *Scenario Development and Costing in Health Care. Methodological Accomplishments and Practical Guidelines*, Utrecht: International Press.
- HOFSTEDE, G. (1991) *Cultures and Organizations, Software of the Mind*, London: McGraw-Hill.
- JAGER, J.C. and VAN DEN BOOM, F. (1994) 'Scenario analysis, health policy and decision making', in E.H. KAPLAN and M.L. BRANDEAU (Eds) *Modelling the Epidemic. Planning, Policy and Prediction*, New York: Raven Press.
- KNMG (1987) 'Richtlijnen inzake euthanasie voor verpleegkundigen', *Medisch Contact*, **42**, 15, pp. 476-9.
- LAANE, H.M. (1995) 'AIDS and euthanasia', in L. SHERR and F. VAN DEN BOOM (guest editors), *AIDS and Suicide. AIDS Care*, **7**, Supplement 2, 19, S. pp. 163-8.
- MCNEILL, W.H. (1976) *Plagues and Peoples*, Garden City: Anchor/Doubleday.
- MINISTERIE VAN WVC (1986) *Gezondheid als Uitgangspunt. Nota 2000 in het Kort*, Den Haag: Ministerie van WVC.
- MINISTERIE VAN WVC (1987) *Nota inzake het AIDS-beleid*, Den Haag: Ministerie van WVC.
- NATIONALE OMBUDSMAN (1995) *Openbaar Rapport. Verzoekschrift van de NVHP met een Klacht over een Gedraging van het Ministerie van WVC*, Den Haag: Nationale Ombudsman.
- NCAB (1995) *Het AIDS-beleid Geactualiseerd. Eindadvies van de Nationale Commissie AIDS Bestrijding*, Amsterdam: NCAB.
- NCCZ (1995) *Werk op Maat. Advies Arbeidsmarktpositie van Mensen met Chronische Gezondheidsproblemen*, Zoetermeer: NCCZ.
- NETHERLANDS MINISTRY OF WELFARE, HEALTH AND CULTURAL AFFAIRS (1992) *AIDS-policy in the Netherlands. Progress Report*, Den Haag: Netherlands Ministry of Welfare, Health and Cultural Affairs.
- POSTMA, M., JAGER, J.C. and DIJKGRAAF, M. (1995) 'AIDS scenarios for the Netherlands: the economic impact on hospitals', *Health Policy*, **31**, pp. 127-50.

- DE RIJK, K. and VAN DEN BOOM, F. (1989) *Psychosociale Hulpverlening AIDS. Vijf Jaar Hulpverlening door de Schorerstichting*, Utrecht: NcGv.
- SCHNABEL, P. (1987) 'Het eigene en het aardige van de geestelijke gezondheidszorg', Rede uitgesproken bij de aanvaarding van het ambt van hoogleraar aan de Universiteit van Utrecht, 13 October.
- SCHNABEL, P. (1989) 'De diepten van een epidemie. Over de maatschappelijke gevolgen van AIDS', in A. NOORDHOFF-DE VRIES (Ed.), *AIDS. Een Nieuwe Verantwoordelijkheid voor Gezondheidszorg en Onderwijs*, Amsterdam: Swets & Zeitlinger.
- SOCIAAL EN CULTUREEL PLANBUREAU (1988) *Sociaal en Cultureel Rapport 1988*, Rijswijk: SCP.
- STG; STEERING COMMITTEE ON FUTURE HEALTH SCENARIOS (1992) *AIDS up to the Year 2000; Epidemiological, Sociocultural and Economic Scenario Analysis for the Netherlands*, Dordrecht: Kluwer Academic Publishers.
- DE SWAAN, A., VAN GELDEREN, R. and KENSE, V. (1979) *Sociologie van de Psychotherapie 2. Het Spreekuur als Opgave*, Utrecht/Antwerpen: Het Spectrum.
- TE VAARWERK, M. TE and GAAL, E. (1995) *Vrouwen met AIDS. Een Onderzoek naar Aard en Omvang van Psychosociale Problematiek*, Utrecht: NcGv.
- WULFF, H. (1995) *Medische ethiek en klinische praktijk. Op zoek naar het juiste evenwicht*, Amsterdam: De Volkskrant.