Stigmatization at the Bed of AIDS Patients: Research into the work of nursing staff caring for AIDS patients from 1983 until 1996

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STIGMATIZATION AT THE BED OF AIDS PATIENTS

Research into the work of nursing staff caring for AIDS patients from 1983 until 1996

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Chapter 1: Introduction

In May 2022, it was announced that the rules for homosexuals to donate blood in the Netherlands would be further relaxed.[1] Until this moment, homosexuals could only donate blood if they had a regular partner. In 2020, they were only allowed to if they had abstained from sexual interaction for four months, and in 2019 for one year.[2] Before that, homosexuals were not allowed to donate blood. This regulation still stemmed from 1983, when AIDS started spreading around the Netherlands. Acquired Immunodeficiency Syndrome (AIDS) is a disease caused by the Human Immunodeficiency Virus (HIV). HIV destroys white blood cells, leading to a lower immune system.[3] Abstaining from donating was one of the many regulations homosexuals had to deal with. Prejudices and judgments on homosexuality became entrenched with AIDS itself.[4] Homosexuals were long seen as the greatest risk group of obtaining AIDS and of spreading the disease.[5] Examples of prejudices and judgment have been found in the United States, where the virus was first discovered, and in the United Kingdom. The United States had a relatively strict policy response to the virus. From 1987 until 2010, there were restrictions for persons with HIV that wanted to enter the country.[6] This was different from the Dutch response, which was seen as relatively calm and pragmatic.[7] This could firstly be explained by the way the Netherlands positioned itself as an open country and welcoming to homosexuals.[8] Secondly, the Netherlands is known for its ‘poldermodel’, making political decisions with those involved being able to participate. I, therefore, expect that prejudices and stigmatization of homosexuals occurred less in the Netherlands than in other countries. This expectation is based on the relative tolerance towards homosexuality and the pragmatic response towards AIDS, by involving risk groups in creating a policy to prevent the spread of the virus. The Netherlands was unique in its approach by involving risk groups in the creation of a policy.[9] However, even in the Netherlands, precautions were taken for specific risk groups.

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[1] *NOS,* ‘Regels voor homoseksuele donoren verder versoepeld’ (25th of May 2022).

[2] *NOS,* ‘Homomannen met vaste partner mogen bloeddonor worden’ (11th of March 2021).

[3] Jorge L. Carro, ‘From Constitutional Psychopathic Inferiority to AIDS: What Is in the Future for Homosexual Aliens?’, *Yale law & policy review* 7 (1989) 201–228., 223

[4] Thomas R, Mendicino, ‘Characterization and disease: homosexuals and the threat of AIDS’, *North Carolina law review* 66 (1987) 226-250, q.v. 226.

[5] Carro, ‘From Constitutional Psychopathic Inferiority to AIDS’, 226.

[6] Ibidem, 227.

[7] Theo, Sandfort, *The Dutch response to HIV : pragmatism and consensus* (London, 1998) 2.

[8] Marlou, Schrover and Frerik Kampman, ‘'Charter flights full of homosexuals'. The Changing Rights of Homosexual Immigrants in The Netherlands, 1945-1992’, *Tijdschrift voor sociale en economische geschiedenis* 16 (2020) 5-36, q.v. 5.

[9] Theo Sandfort, *The Dutch response to HIV*, 3.

As stated above, homosexuals were asked to restrict from donating blood altogether.[10] To research whether the stigmatization of homosexuals occurred in the Netherlands, I will investigate the experiences of nurses from 1983 until 1996. This covers the point from when the first few patients were diagnosed with AIDS in the Netherlands, until 1996 when HIV became a chronic, instead of deadly, disease with the discovery of new medicines that intervened earlier in the process.[11] Nurses were the professional group that got in touch with AIDS patients more than any other profession. They were the ones taking care of and getting in touch with these patients. Nurses played a leading role in fighting the stigmas surrounding AIDS. In the Netherlands, a new specialisation of nursing AIDS consultants was created. These consultants held consultation hours and offered psycho-social care to their patients.[12] This is an example of the great influence nurses had on the care their patients received. How they interacted with their patients, must have been influenced by the information they had on the disease and must have influenced, at least their own, stigmatization of risk groups. I am curious to figure out how they obtained information on the spread of the virus and how this influenced their caregiving. Furthermore, the viewpoint of the nurse is still very left out of Dutch AIDS literature. Research has been done in archival sources and interviews have been held with, for example, policymakers, doctors, and patients.[13] The experiences and views of those interacting most with these patients have so far been left out of the research. Therefore, I think it is important to include their experiences to obtain a broader view of the spread of HIV and the treatment of AIDS patients in the Netherlands. For this research, seven nurses have been interviewed about their experiences of working with AIDS patients. Furthermore, information material specifically meant for healthcare personnel during this period was analysed. My research questions are: "How did information on caring for AIDS patients handed out to healthcare personnel from 1983 until 1996 influence the stigmatization of homosexuals and how did nurses experience this period?"

1.1 Theoretical framework

This research aims to investigate whether the information given out to healthcare personnel in the Netherlands has led to the stigmatization of homosexuals. To define stigmatization, I use the definition that was given by Stutterheim et al.: "*A stigma is a distinctive, discrediting*

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[10] Mariëlle Hageman, *Aids in Amsterdam* (Amsterdam, 2018), 12.

[11] Annet de Mooij, *Geen Paniek!: Aids in Nederland 1982-2004* (Houten 2004), 132.

[12] Hugo Schalkwijk & Pieterbas Lalleman, 'Van Krim tot Corona', *Impact Magazine* 1 (2021) 34-37, q.v. 36.

[13] See, for example, Annet de Mooij, *Geen Paniek!: Aids in Nederland 1982-2004* (Houten 2004), Theo Sandfort, *The Dutch Response to HIV: Pragmatism and Consensus* (London 1998) and Mariëlle Hageman, *Aids in Amsterdam* (Amsterdam 2018).

characteristic that renders its bearer tainted, flawed, or inferior in the eyes of others.”[14] Stutterheim is an interdisciplinary researcher with expertise in the fields of health and social psychology, health promotion and education, and public health.

Stigmatization has been widely researched and many conceptualisations exist. In 1963, sociologist Erving Goffman published a book on the idea of a stigma.[15] Since then, much research has been done into stigmas. The term stigma stems from the Greek and most recent conceptualisations include the recognition of devaluation and emphasize that stigma occurs in social interactions.[16] Research into stigmatization has been done by psychologists, sociologists, and sociomedical sciences. Phelan, a special research scientist in sociomedical sciences, has demonstrated that stigmatization can have multiple functions.[17] Kurzman and Leary, both psychologists, have indicated one of these functions as disease avoidance. From an evolutionary perspective, the stigmatization of the diseased can be explained.[18] Not only patients are affected by stigmatization, but also those connected to them or associated with them.[19] This could indicate that homosexuals were affected by stigmatization since they were associated with AIDS patients. Research by Herek, a psychologist, has shown that stigmatization of homosexuals did occur in the United States.[20] I will research whether stigma has occurred by using Stutterheim’s definition. She has done much research into the stigmatization of AIDS patients. Her research has shown that having a visible stigma is more prejudicial than having a concealable stigma.[21] Furthermore, a comparison of data on the stigmatization of persons with HIV from 2007 and 2009 with data from 2019 and 2020 has shown that stigmatization in the healthcare sector, specifically in hospitals, has risen.[22] Recognizable factors of stigma are when people would keep a distance from patients, take unnecessary precautions, or show discomfort. These factors will be used in this research.

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[14] Sarah Stutterheim et al., ‘Psychologiscal and social correlates of HIV status disclosure: The significance of stigma visibility’, *AIDS education and prevention* 23 (2011), 382-392, q.v. 382.

[15] Erving Goffman, *Stigma: Notes on the Management of Spoiled Identity* (New York 1986).

[16] Arjan Bos et al., ‘Stigma: Advances in Theory and Research’, *Basic and Applied Social Psychology* 35:1 (2013), 1-9, q.v. 1.

[17] J.C. Phelan, B.G. Link & J.F. Dovidio, ‘Stigma and prejudice: One animal or two?’ *Social Science and Medicine* 67 (2008) 358-367.

[18] Kurzban , R. , & Leary , M. R., ‘Evolutionary origins of stigmatization: The functions of social exclusion’, *Psychological Bulletin* 127 (2001) 187-208.

[19] Bos et al., ‘Stigma’, 4.

[20] G.M. Herek, ‘AIDS and stigma’, *American Behavioral Scientist* 42 (1999) 1106-1116, q.v. 1110.

[21] Stutterheim et al, ‘Psychological and social correlates of HIV status disclosure’, 382.

[22] Sarah Stutterheim et al., ‘Trends in HIV Stigma Experienced by People Living with HIV in the Netherlands: A Comparison of Cross-Sectional Surveys Over Time’, *AIDS Weekly* (2021) 33-52, q.v. 52.

1.2 Historiography

Many authors have already written about AIDS and homosexuality. Most research focuses on the United States, where the spread of AIDS started. An example is the extensive report of the National Research Council that reviews the impact of the AIDS epidemic on social and cultural institutions.[23] The most important conclusion from this research is that the epidemic has hit disadvantaged people, such as the poor, the hardest.[24] Thomas Mendicino and Jorge Carro both researched the possibility and effects of a travel ban for people with HIV to the United States from a legal perspective in the late eighties.[25] Furthermore, both Carro and Mendicino show that the homosexual community became the target of homophobic reactions because AIDS was seen as a gay man's disease.[26] Some AIDS research has also been done in the Netherlands. Theo Sandfort, a social psychologist, has done research into homosexuality in the Netherlands and the Dutch policy to combat AIDS. In 1998, he published a case study on the Dutch response in collaboration with many other researchers. The Dutch response was pragmatic and was based on consensus, due to the many groups that were involved in creating it.[27] The contributions in this book explore a variety of issues. The first part describes prevention aimed at various groups, the second section researches broader political issues, such as the healthcare response. Finally, the results of several Dutch studies are presented. Contributors are (social) psychologists, sociologists, health professors, and persons active in the AIDS policy, such as Hans Moerkerk who was International AIDS Advisor to the Ministry of Health, Welfare, and Sport.[28] Another author that has published an extensive work on the Dutch AIDS Policy is Annet Mooij, a social scientist. Her work 'Geen Paniek!' also refers to the pragmatic approach of the Dutch government to combat AIDS. This work was published in 2004 and is based on archival sources of, for example, the Ministry of Health, Welfare and Sport and interviews with doctors and policymakers. She also describes the struggles and arguments occurring in the different working groups that were set up.[29] The pragmatic Dutch policy was also described and evaluated by Duyvendak and Koopmans, both sociologists, already in 1991. They researched the influence of a strong gay movement on the spread of AIDS. In their research, they compared the

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[23] National Research Council, *The Social Impact of AIDS in the United States* (Washington D.C. 1993)

[24] Ibidem, 8.

[25] Thomas R Mendicino, 'Characterization and disease: homosexuals and the threat of AIDS', *North Carolina law review* 66 (1987) 226-250. & Jorge L. Carro, 'From Constitutional Psychopathic Inferiority to AIDS: What Is in the Future for Homosexual Aliens?', *Yale law & policy review* 7 (1989) 201–228.

[26] Carro, 'From Constitutional Psychopathic Inferiority to AIDS', 226 & Mendicino, 'Characterisation and disease', 229.

[27] Theo Sandfort, *The Dutch response to HIV: pragmatism and consensus* (London 1998).

[28] Sandfort, *Pragmatism and Consensus,* 263-267.

[29] Annet Mooij, *Geen paniek! Aids in Nederland, 1982-2004* (Amsterdam 2004).

prevalence of AIDS in several European countries. The results indicate that the existence of an educated gay community, as was present in the Netherlands, has had a negative influence on the prevalence of AIDS, but was beneficial to the possibilities of prevention because the community was easy to reach.[30] In 2018, the book 'Aids in Amsterdam' was published by Mariëlle Hageman, a historian. This book was commissioned by the Amsterdam City Archives, the Diversity Department of the Municipality of Amsterdam, and the Amsterdam Municipal Health Service. Sources used were newspaper articles, the archives of Aidsfonds, and the municipality of Amsterdam. The book was published in honour of the 22nd International AIDS Conference in Amsterdam and gives an overview of the impact AIDS had on the city and the important persons that played a role. In an article in *'Historisch Nieuwsblad'* (Historical newspaper), Hageman describes that AIDS led to a new hierarchical order between patient and doctor. Patients were aware of the developments surrounding HIV and AIDS, often as good as their doctors or even better.[31]

Between 1983 and 1996, three separate periods can be distinguished. These periods have been indicated based on the contribution of Van den Boom and Schnabel. Van den Boom works in global health and Schnabel is a sociologist. They researched the impact of AIDS on the Dutch Health Care System.[32] They identify three landmarks that distinguish the different periods: first 'bloody Sunday' in 1983, during which it was decided that homosexuals would be advised to withdraw from blood donation. The second landmark is a meeting at the National Institute of Public Health in 1986 during which it was decided that the entire population should be targeted in campaigns, instead of just risk groups. The third landmark is the revision of the AIDS policy by the Dutch scenario study in 1991. The risk of an enormous spread of AIDS among the entire population stayed out. The first period is characterized by uncertainty and fear. The AIDS policy was coordinated by the National AIDS Policy Coordination Team. The second period is characterized by the discussion on legal and ethical issues of, for example, testing for HIV. AIDS policy was coordinated by the National Committee on AIDS Control from 1987 onwards. The third period was characterized by issues of care and treatment.[33] In 1996, the combination treatment was allowed on the Dutch market, which turned AIDS from a deadly into a chronic

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[30] J.W. Duyvendak and R. Koopmans, 'Weerstand bieden aan aids; de invloed van de homobeweging op de aids-preventie', *Beleid & Maatschappij* 5 (1991), 237-245.

[31] Mariëlle Hageman, 'De opkomst van aids', *Historisch nieuwsblad: tweemaandelijks magazine over geschiedenis en het historisch bedrijf* 6 (Amsterdam 2018), 65.

[32] Frans van den Boom and Paul Schnabel, 'The Impact of AIDS on the Dutch Health Care System', *The Dutch Response to HIV: Pragmatism and Consensus* by Theo Sandfort, 153-174.

[33] Janherman Veenker, 'The Decisive Role of Politics: Aids Control in the Netherlands', *The Dutch Response to HIV: Pragmatism and Consensus* by Theo Sandfort (London 1998), 121-134, qv 122.

disease.[34] From 1995 onwards, coordination of the AIDS policy was done by the Dutch Aidsfonds.[35] It is necessary to distinguish these periods because, in these different periods, guidelines on treating AIDS patients were different, discussions were centred around different topics and the available information known on transmission was different. To verify whether these periods add up to the differences in knowledge, 120 primary sources, such as articles in journals for nurses, were reviewed. A similar pattern as was described in the literature was identified.

The first AIDS patient was identified in 1981 in the Amsterdam Medical Centre.[36] In 1982, during a symposium in Rotterdam, the first two Dutch cases of AIDS were presented. At that time, Amsterdam was known as an open, tolerant city that had many gay bars, hotels, restaurants, saunas, and sex clubs. This attracted many gay tourists and led to a rapid spread of the disease in the city.[37]

1.2.1 Period 1: 1983 until 1986

The first AIDS awareness campaign started in 1983.[38] There was fear of stigmatization of risk groups in the coordinating team, which was one of the reasons that risk group organizations were invited to exert their influence.[39] This led to the creation of an informal National AIDS Policy Coordination Team, funded by the Ministry of Health.[40] On January 30, 1983, AIDS was first acknowledged as a problem in the Netherlands. Later that day became known as 'Bloody Sunday'. The collective decision was made that gay men should withdraw from donating blood voluntarily instead of mandatorily.[41] This was the first restriction that was made in the Netherlands. By this moment, AIDS was already rapidly spreading in the United States, so it was somewhat known how the virus spread. However, some media did report inaccuracies.[42] Between 1983 and 1987, prevention activities were not directed at the public at large, but at risk groups.[43] For homosexuals, the 'double message' persisted. In other countries, homosexuals were advised to use condoms while having anal sex. In the Netherlands,

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[34] Hageman, *Aids in Amsterdam,* 47.
[35] Veenker, 'The Decisive Role of Politics', 122.
[36] Hageman, *Aids in Amsterdam*, 6.
[37] Ibidem, 12.
[38] Mooij, *Geen paniek!*, 17.
[39] Ibidem, 91.
[40] Theo Sandfort, 'Pragmatism and Consensus: The Dutch Response to HIV', in *The Dutch Response to HIV: Pragmatism and Consensus* by Theo Sandfort (London 1998) 3-19, q.v. 9.
[41] Boom et al., 'The Impact of AIDS on the Dutch Health Care System', 157.
[42] Sandfort, 'Pragmatism and Consensus', 11-12.
[43] Veenker, 'The Decisive Role of Politics', 125.

homosexuals were advised to refrain from anal sex altogether, but if they could not, to use a condom.[44] This advice lasted until 1992. In 1984, the ‘spuitomruil’ program was introduced, a program that allowed drug users to exchange used needles for clean ones.[45] At the end of 1984, a blood test that could show antibodies was introduced. From 1985 all blood at blood banks became systematically tested for antibodies. However, homosexuals were still discouraged from donating blood due to the window period of the test.[46] In 1985, a fund was set up in consultation with the COC, the Aidsfonds.[47] The fund started raising money for research and prevention activities. Furthermore, from 1985 onwards, the first flyers for people at risk of contracting AIDS during their work appeared.[48]

1.2.2 Period 2: 1987 until 1990

The period from 1987 until 1991 was dominated by concern for legal and ethical issues.[49] This was partly due to the possibility to test for antibodies of HIV. Testing was discouraged because there was no cure and a negative result might give a false sense of security.[50] This period started with a turnaround in the political debate due to a new government. Dick Dees (VVD, liberal party) became the new state secretary of Health and became very active in combatting AIDS, due to pressure from society.[51] From 1987 onwards, the main goal of public campaigns was to detach AIDS from risk groups. Prevention campaigns were now aimed at the entire public.[52] Until this moment, epidemiological data did not indicate that the general public was at risk.[53] That changed. This indicates that HIV was spread easier and through more ways than was believed in the first instance. In 1987, the National Committee on AIDS Control (NCAB) was established. This was a more formal committee, as opposed to the Coordination Team. The influence of homosexual organizations became more limited.

In May 1987, a report from the Center for Disease Control (CDC) reported that three healthcare workers had become infected with HIV in the United States.[54] In 1987 HIV was added to the

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[44] Theo Sandfort, Marty van Kerkhof & Onno de Zwart, ‘No Anal Sex Please: We’re Dutch. A Dilemma in HIV Prevention Directed at Gay Men’, in *The Dutch Response to HIV: Pragmatism and Consensus* by Theo Sandfort (London 1998) 135-152, q.v. 135.

[45] Annet Mooij, *Geen paniek!* 29-30.

[46] Ibidem, 39.

[47] Hageman, *Aids in Amsterdam*, 14.

[48] Ibidem, 16.

[49] Janherman Veenker, ‘The Decisive Role of Politics’, 122.

[50] Theo Sandfort, ‘Pragmatism and Consensus’, 7.

[51] Annet Mooij, *Geen paniek!* , 177.

[52] Ibidem, 77.

[53] Janherman Veenker, ‘The Decisive Role of Politics’, 125.

[54] National Research Council, *The Social Impact of AIDS in the United States,* 59.

list of dangerous contagious diseases in the US.[55] Persons travelling to the United States did not have to be tested, but carrying medicine or other indications of being infected, could lead to detainment. The United States already had a law restricting travelling into the country for certain groups of people. In 1917, the Immigration Act was implemented. This act excluded homosexuals to travel to the United States because homosexuality was seen as a disease.[56] The travel ban was used to prevent the spread of (infectious) diseases. This ban changed throughout the years and homosexuality was not seen as a mental illness anymore. The travel ban from 1987 was widely criticized. More attention was given to the travel ban executed by the United States when Hans Paul Verhoef, chairman of the HIV association, travelled to the United States for the AIDS Conference in 1989. He was advised to not declare to have AIDS but was still carrying a letter that declared him to have to pay no fee for the conference because of having AIDS. For this, he was detained. Eventually, during his hearing, he had to declare that he would act "safely" and that his presence was important for the conference. After this incident, it became allowed to enter the United States when being seropositive if it was for business for a maximum of thirty days.[57] This incident caused much upheaval, both in the Netherlands and in the United States.

1.2.3 Period 3: 1991 until 1996

In the period from 1991 until 1995, the debate in the Netherlands was focussed on issues of care and treatment.[58] In the early nineties, the Dutch Scenario Study prepared a revision of the AIDS policy. Both in terms of size and costs, it became apparent that AIDS would not become as big of a problem as was thought before.[59] HIV did not spread as easy as was thought before. In 1992, the 'double message' was changed. It now became advised to use condoms.[60] That same year, the Aidsfonds merged with the NCAB.[61] From 1995 onwards, Aidsfonds became responsible for the AIDS policy in the Netherlands.[62] From that moment, safe sex campaigns became aimed at sexually transmitted diseases in general. In 1996, a new generation of medicines was discovered. A combination of medicines could suppress HIV, which prevented

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[55] Carro, 'From Constitutional Psychopathic Inferiority to AIDS', 224
[56] Carro, 'From Constitutional Psychopathic Inferiority to AIDS', 208
[57] Henk de Greef, 'Begrensde Mogelijkheden', *hiv nieuwsbrief,* 1:89, 4-5.
[58] Janherman Veenker, 'The Decisive Role of Politics', 122.
[59] Boom et al., 'The Impact of AIDS on the Duthc Health Care System', 161.
[60] Sandfort et al., 'No Anal Sex Please', 135.
[61] Hageman, *Aids in Amsterdam,* 15.
[62] Janherman Veenker, 'The Decisve Role of Politics', 121.

the development of AIDS. These medicines were allowed on the Dutch market faster than usual.[63]

1.2.4 Fear among healthcare workers

In the United States, it was unclear how the virus spread when the first cases were identified. Before the modes of transmission were fully understood, many healthcare workers feared contact with AIDS patients.[64] A study conducted among healthcare personnel in 1991, showed that nurses expressed the most worry and discomfort (in comparison to physicians and social workers).[65] A second study showed that medical personnel could be concerned when working with AIDS patients. Most concerns were related to the transmission of the disease.[66] This is in line with the findings of other studies. The answers to a questionnaire that was sent out to hospitals and was filled out by 364 nurses, showed that most respondents were concerned for their safety.[67] Another study was performed in 1985 to test the levels of homophobia among nurses and medical house officers. Both doctors and nurses fell in the low-grade homophobic range.[68] Almost ten percent of all respondents agreed with the statement that "*homosexuals who contract AIDS are getting what they deserve".*[69] All these studies were conducted in the eighties or early. Especially the last study shows that stigmatization was common among healthcare workers.

The literature that is already available, either focuses on other countries or the creation of the Dutch policy. This focus is easily explained by the uniqueness of the involvement of interest organizations. However, what still misses is what kind of effect the public information campaigns and regulations regarding healthcare workers have caused. Furthermore, even though policymakers and doctors have been interviewed to show their experiences, nurses have not been involved in research yet. They are the ones that had the most patient contact and might have had the least influence on the policy. Therefore, it is interesting to see their perspective. The above section has shown quantitative research into the fear and experience of nurses in the eighties and nineties. However, this research is aimed at the United States instead of the

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[63] Annet Mooij, *Geen paniek!,* 133.

[64] National Research Council, The Social Impact of AIDS in the United States, 11.

[65] Joan Dworkin, Gary Albrecht & Judith Cooksey, 'Concern about aids among hospital physicians, nurses and social workers', *Social science & medicine* 33 (1991) 239-248 q.v. 243.

[66] F.A. Treiber, D. Shaw and R. Malcolm, 'Acquired Immune Deficiency Syndrome: psychological impact on health personnel', *Nervous Mental Disorder* (1987) 496-499, q.v. 496.

[67] L. Brennan, 'The battle against AIDS: a report from the nursing front', *Nursing* 18 (1988) 60-64 q.v. 61.

[68] Carolyn Douglas, Concetta Kalman and Thomas Kalman, 'Homophobia Among Physicians and Nurses: An Emprical Study', *Hospital & Community Psychiatry* 36:12 (1985) 1309-1311, q.v. 1309.

[69] Ibidem.

Netherlands. Finally, research was done during the period AIDS was still rapidly spreading. It is unclear how these nurses look back at their experiences. The Global Health Chronicles, a historic collection of, among other documents and images, interviews with past employers of the CDC in the United States is an example of research into the experiences of those researching or working with AIDS patients. However, no nurses were included in this research. I would like to fill this gap in the literature by focussing on the information and instructions given to healthcare workers and the experience of nurses themselves.

1.3 Material and Method

Besides analysing the existing literature on this topic, I will use two sets of primary sources. Sources from the period 1983 until 1996 will be used to analyse whether there are differences between the three periods, as discussed in section 1.2.

Firstly, seven nurses were interviewed about their experience of working with AIDS patients. The goal of these interviews is to find out what they and their environment thought of them working closely together with persons carrying a contagious disease and how they experienced this period. I wonder whether there was much misinformation on how the virus could be spread among these healthcare workers. The interviews were semi-structured. Before conducting them, a list of possible questions and themes was made. Using interviews as a research method is a form of oral history. Oral history is the method of collecting narratives from individuals for research.[70] It is 'the recording of personal testimony delivered in oral form with purposes beyond the recording itself.'[71] This was first established as a technique for historical research in 1948 when historian Allan Nevins recorded the memoirs of persons that were significant in American Life.[72] One limitation of the use of interviews is that interviewees can be hard to find or unwilling to participate and that their memories can be distorted or faded. However, I do not think that is a disadvantage in this research. The aim of using these interviews is not to find out facts about the situation at that time, but to get an idea of the experiences and memories of the interviewees. Furthermore, inaccuracies in the experience of the participants can be checked by consulting other sources.[73] Oral history is a useful tool to conduct historical research since it can discover something that has not been found before.[74] Furthermore, macro-micro linkages

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[70] Patricia Leavy, *Oral history* (New York 2011) 5.

[71] Valerie Raleigh Yow, *Recording oral history: a guide for the humanities and social sciences* (Third edition; New York 2015), 4

[72] Leavy, *Oral* history,3.

[73] Yow, *Recording oral history*, 55.

[74] Yow, *Recording oral history,* 6.

can be made by comparing and connecting the experiences of the participants with the historical context and other primary sources.[75]

Seven interviews with nursing staff were conducted. Four of these interviews were held online and three in-person. The choice was given to the participant on where the interview was conducted. Of the three in-person interviews, one person was interviewed at their work and two persons were interviewed at their home. At first, two participants were selected. Through the snowball method, other participants were found. The interviews will be analysed through thematic analysis. This allows for a comparison between the different interviews. As has been described by Yow, oral history interviews can be analysed and compared by identifying the different important themes within the interviews and then describing what each participant experienced or by clustering similar experiences together.[76] Before conducting the interviews, three general topics were established, around which the questions were centred. The main questions were: what did you think of caring for patients with AIDS, what did your personal environment think about this, and do you think you had a different view on AIDS due to their work. The topics were patient care, precautions, and stigmatization. After having conducted all interviews, the interviews were analysed and the distinction between experiences within the working environment and experiences in the personal environment was made. In the personal environment, the memory of the view portrayed by general media was included. All interviews were analysed and compared on the different themes. Finally, the interviews were compared with the primary sources and the literature to be able to make a comparison of the different periods.

Table one gives an oversight of all participants. All participants have followed the training to become a nurse and have dealt with either the creation of regulations around AIDS patients or with AIDS patients themselves. In table one, it also becomes visible during which period (as identified in the historiography), they were mainly active in the working field.

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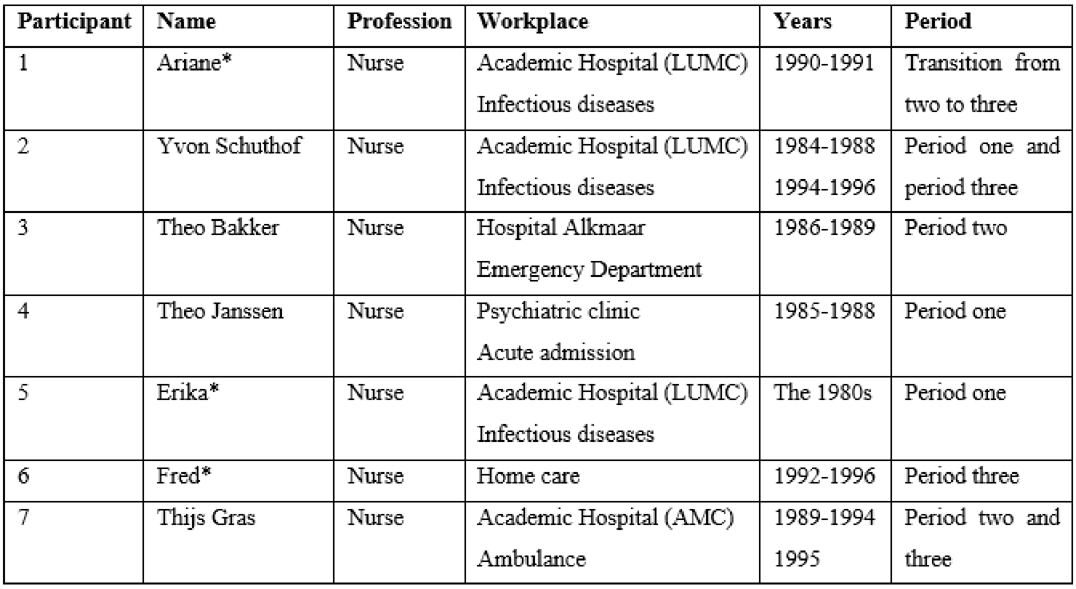
[75] Leavy, *Oral history,* 16.

[76] Yow, *Recording oral history,* 325.



Participant	Name	Profession	Workplace	Years	Period
1	Ariane*	Nurse	Academic Hospital (LUMC) Infectious diseases	1990-1991	Transition from two to three
2	Yvon Schuthof	Nurse	Academic Hospital (LUMC) Infectious diseases	1984-1988 1994-1996	Period one and period three
3	Theo Bakker	Nurse	Hospital Alkmaar Emergency Department	1986-1989	Period two
4	Theo Janssen	Nurse	Psychiatric clinic Acute admission	1985-1988	Period one
5	Erika*	Nurse	Academic Hospital (LUMC) Infectious diseases	The 1980s	Period one
6	Fred*	Nurse	Home care	1992-1996	Period three
7	Thijs Gras	Nurse	Academic Hospital (AMC) Ambulance	1989-1994 1995	Period two and three

Table 1. Overview of participants[77]

The second set of sources that will be used are articles in magazines aimed at healthcare personnel and other articles about the care for AIDS patients. These articles are analysed to investigate whether the information given out to healthcare personnel influenced the stigmatization of homosexuals. Four magazines were analysed. The archive of the HIV association and the Association SOA AIDS Nederland (and its precedents) were reviewed. From this, multiple articles in *SOA-Bulletin*, *HIVNieuws*, and specific magazines for nurses were found relevant. To confirm whether the three periods indicated in the historiography added up with the primary sources, more than 140 articles were scanned. It became apparent that the division in the three periods corresponded with both the literature and the primary sources. From the four magazines, the most relevant articles concerning the care for AIDS patients were extracted. All articles that were published in a transition period between different periods, were analysed through discourse analysis.

To research whether there is a difference in the coverage of AIDS in informative articles for healthcare personnel during the three periods, discourse analysis has been used. There are different methods of conducting a discourse analysis.[78] In this research, the method of argument

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[77] All names with an asterisk are pseudonyms. To protect the privacy of the participants, pseudonyms were made up for three participants. Furthermore, to distinguish between Theo Bakker and Theo Janssen, Theo Bakker will be referred to as 'Theo', while Theo Janssen will be referred to as 'Theo Janssen'.

[78] Bauder, H., 'Media discourse and the new German immigration law', *Journal of Ethnic and Migration Studies 34*, 1 (2008) 95–112, 102.

analysis has been chosen. Argument analysis examines models of argumentation and schemes of thought in the written text.[79] This has been done by identifying frames in the articles. Frames are a series of ideas that make it possible to identify causes and problems. They can be derogatory and have a negative connotation.[80] Authors can consciously and unconsciously use frames to make text recognizable. A top-down approach has first been used to analyse which frames can be found in the articles. This entails identifying generic frames in the articles. Several generic frames have already been identified by various authors in migration research.[81] The generic frames that could be identified are the economic frame, the humanitarian frame, the legalistic frame, the security frame, and the cultural frame. These frames are also applicable to this research because the argument behind them remains the same. The economic frame can be identified when economic gain or loss is discussed. The humanitarian frame can be identified in articles that ask for empathy or sympathy for those having contracted AIDS or homosexuals. The legalistic frame emphasizes rules and regulations as an argument for something. The security frame can be identified in articles that speak of AIDS or homosexuals as a threat to Dutch society. Lastly, the cultural frame emphasizes Dutch culture. Even though these frames are generally used to conduct migration research, they are also applicable for this research. By identifying frames in the articles, it will be possible to analyse whether argumentation has changed over time. During the analysis, a new frame was identified. This is the ‘nuance’ frame and applies to articles that nuance the risks of the virus or refer to risks for others than the general risk groups. Finally, when no frame was found in the articles, but they were still relevant for the research, the label ‘other’ was given. The analysed articles provided relevant information on three themes: patient care and interest, the transmission of the virus, and stigmatization.

The magazines that were used are *SOA-Bulletin* from the association SOA Aids Nederland, *HIVNieuws* from the HIV Association, *Tijdschrift voor Ziekenverpleging* (Magazine for Nursing), and *Tijdschrift Verpleegkunde* (Nursing Magazine). In total, 54 articles were analysed.

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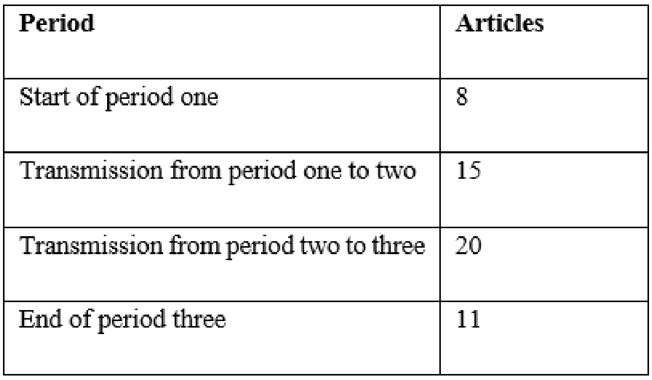
[79] Bauder, H., ‘Media discourse’, 102.

[80] Willem Schinkel & Marlou Schrover, ‘Introduction: The language of inclusion and exclusion in the context of immigration and integration’, *Ethnic and Racial Studies* 36 (2013) 1123-1141, q.v. 1129.

[81] Marlou Schrover and Tycho Walaardt, ‘The Influence of the Media on Policies in Practice: Hungarian Refugee Resettlement in the Netherlands in 1956’, *Journal of Migration History* 3 (2017) 22–53, q.v. 27–28.



Period	Articles
Start of period one	8
Transmission from period one to two	15
Transmission from period two to three	20
End of period three	11

Table 2. Number of articles per period

SOA Aids Nederland has as its goal to spread information to practitioners to patients.[82] For the spread of information to practitioners, the *SOA-Bulletin* was created. This magazine was published every two months and distributed among various sectors of healthcare workers. It is subsidized by the Ministry of Health, Welfare, and Sport.[83] From 1985 until 1991, the magazine contained a permanent column "*recent developments surrounding AIDS*". This section was written by Jan van Wijngaarden, national AIDS coordinator, and his successor Bart Eijrond. With Eijrond's departure as head of the NCAB, the column came to an end.[84]

HIVNieuws started as a joint publication of the 'Belangenbehartiging Sero-Positieven' (Seropositive Association) and the 'Belangenvereniging Mensen met Aids' (Association of People with AIDS). The newsletter aims to keep HIV-infected people and healthcare workers informed about the news and activities surrounding AIDS. This newsletter replaced the original newsletter of the Belangenbehartiging Sero-Positieven and was published every two months.[85] In August 1989, both associations merged.[86] Of this magazine, editions one to 43 were reviewed. Edition 41 and 42 were not present in the archive of the HIV Association and have not been analysed. In the analysis, articles aimed at healthcare or about care for AIDS patients were included. Among other authors, articles are written by Jeannette Kok, nurse and board

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[82] Nationaal Archief, 2.19.225, I77, Stichting Aids Fonds – Soa Aids Nederland, de Stichting STOP AIDS NOW! En de Stichting Werkmaatschappij Soa Aids en hun taakvoorgangers, Inventory number 36, SOA Stichting, *Jaarverslag 1983* (Utrecht, 1984) 8.

[83] Nationaal Archief, 2.19.225, I77, Stichting Aids Fonds – Soa Aids Nederland, de Stichting STOP AIDS NOW! En de Stichting Werkmaatschappij Soa Aids en hun taakvoorgangers, Inventory number 71, SOA Stichting, *Bijdrage aan het jaarboek 1993/1994 van de Nederlandse Vereniging voor Dermatologie en Venereologie en de 'Commissie-Marathon'van de NVDV* (1994) 1.

[84] Nationaal Archief, 2.19.225, I77, Stichting Aids Fonds – Soa Aids Nederland, de Stichting STOP AIDS NOW! En de Stichting Werkmaatschappij Soa Aids en hun taakvoorgangers, Inventory number 43, SOA Stichting, 'SOA-Bulletin', *Jaarverslag 1991* (1992) 42.

[85] HIV Vereniging, Department HIV Nieuws, Inventory number 464, *hiv nieuwsbrief* (1989), 1, 1.

[86] HIV Vereniging, *hiv nieuwsbrief* (1989), 1, 3.

member of the interest group for people with AIDS, and Tineke van der Kruk, who worked on the AIDS department of the AMC.

Finally, two magazines specifically aimed at nurses were analysed. The first is the ‘Tijdschrift voor Ziekenverpleging’ (Magazine for Nursing of the Ill, TvZ). This magazine has been published since 1890.[87] It contains many detailed articles on different diseases. Among other authors, articles were written by Klaas Hoeksema, initiator of the profession of AIDS nursing consultant. All editions from 1988 until 1996 were analysed. Finally, the ‘Tijdschrift voor Verpleegkunde’ (Nursing Magazine, TV) was reviewed. The goal of this magazine is to spread high-quality knowledge on the discipline of nursing.[88] Editions six (1992), seven (1992 and 1993), nine (1994 and 1995), ten (1995), and eleven (1996) were present at the University Library and studied for this research. However, only one relevant article on AIDS was found.

The analysis will be done separately for the interviews and the other primary sources. The first hypothesis is that these sources show little to no stigmatization of homosexuals. The second hypothesis is that rules and regulations become less strict and more positive as more is known about the contamination of HIV. The final hypothesis is that, once the first case of AIDS was found in the Netherlands, enough information about the spread of the disease was already known, so there was no communication of misinformation or extra precautions towards healthcare personnel. This, in turn, has led to less stigmatization in the Netherlands than in other countries.

1.3.1 Conceptualisation

The first concept that should be conceptualised is that of homosexuality. Homosexuality is defined as having sexual feelings for someone from the same gender.[89]

Within this thesis, I refer to the word AIDS to refer to HIV Stage 3. AIDS was first referred to as Gay-Related Immune Disease (GRID), but that name was changed to Acquired Immune Deficiency Syndrome in 1982 since the disease did not only affect homosexuals.[90] AIDS is a disease that is caused by HIV, which was discovered in 1984. Infection with HIV does not mean that a person develops AIDS straight away, but that person can pass the infection.[91] HIV infects

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[87] TvZ, *Contact* via https://www.tvznext.nl/contact/

[88] Tijdschrift Verpleegkunde, *Over Verpleegkunde* via https://tijdschriftverpleegkunde.nl/colofon/over.html

[89] Definition by Van Dale

[90] Mooij, *Geen paniek!*, 4.

[91] Hageman, AIDS in Amsterdam, 7.

the white blood cells, which results in a lower immunity to infections and diseases.[92] HIV can be present in blood, semen and pre-cum, vaginal fluid, and breast milk. There is a risk of transmission if any of these body fluids come into contact with a person's bloodstream or mucous membranes.[93] Currently, there is no risk of transmission if a person is treated for their HIV infection.[94] In this research, the word AIDS will be used more often than HIV, to indicate their condition. Patients that were cared for by the nurses that were interviewed, had AIDS.

1.3.2 Structure

This thesis will be divided into three chapters. The first chapter will be an analysis of the information that was spread among healthcare personnel and within healthcare organizations. This chapter will be based on the *SOA-Bulletin*, *HIVNieuws*, the *TvZ,* and the *TV*. This chapter will answer the question: how did the information given to healthcare workers influence the stigmatization of homosexuals? The second chapter will analyse the experiences of nurses in their work environment. This chapter will answer the question: how did nurses experience working with AIDS patients from 1983 until 1996?

The final chapter will analyse the experiences of nurses in their personal environment. This chapter will answer the question: was there less stigmatization under nurses than under the rest of society?

Based on these three chapters, a conclusion will be drawn surrounding the spread of information on AIDS in the Netherlands. This thesis aims to answer the following research questions: "How did information on caring for AIDS patients handed out to healthcare personnel from 1983 until 1996 influence the stigmatization of homosexuals and how did nurses experience this period?"

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[92] Carro, 'From Constitutional Psychopathic Inferiority to AIDS', 223.

[93] Aidsfonds, *Hoe loop je hiv op?* Via https://aidsfonds.nl/over-hiv-aids/wat-zijn-hiv-en-aids/hoe-loop-je-hiv-op/

[94] Aidsfonds, *Niet meetbaar = niet overdraagbaar* via https://aidsfonds.nl/over-hiv-aids/feiten-en-cijfers/niet-meetbaar-niet-overdraagbaar/

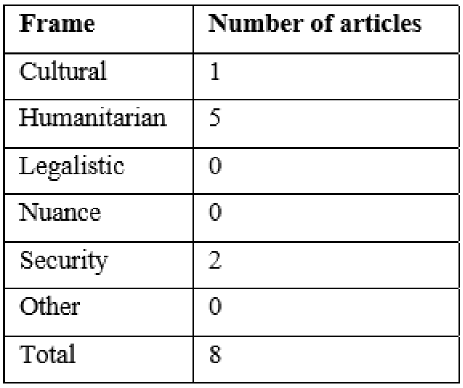
Chapter 2: Instructions for healthcare personnel

This chapter will describe what information was given to healthcare workers. The magazines that will be used are *TvZ*, *Tijdschrift Verpleegkunde,* and the *SOA-Bulletin*. In total, 54 articles were analysed. As stated above, discourse analysis was conducted to identify different frames in the articles. Three general themes were identified to further analyse the magazine articles. These themes are patient care and interest, the transmission of the virus, and stigmatization.

The articles that will be analysed stem from the transition from one period to another. This will indicate whether the changes that occurred in policy and debates, were also visible in the information available to healthcare personnel. Four transitional moments will be analysed. The first is the start of the AIDS policy and the period during which the first patients entered the hospital in 1983 and 1984. Not all information on the disease and its spread was known. The second moment is the transition from period one until period two. It had become evident that the spread of AIDS would not be limited to risk groups. Thus, it had become clear that the disease could be spread via other forms of sexual contact than just anal sex. The third moment is the transition from period two to three. It became apparent that HIV would not spread as fast as was initially feared. During this transition, it became clear that HIV was less easily transmitted than thought before. The final moment is the end of period three, during which working medicines were invented.

2.1 The start of period 1: 1983 -1984

During the first period, eight relevant articles were found. In these articles, the humanitarian frame was most dominant. All articles in this period were published in the *SOA-Bulletin*. Most articles were published by Jan van Wijngaarden, National AIDS Coordinator, in the column 'recent developments surrounding AIDS'.



Frame	Number of articles
Cultural	1
Humanitarian	5
Legalistic	0
Nuance	0
Security	2
Other	0
Total	8

Table 3. Number of articles per frame at the start of period 1

2.1.1 Patient care and interest

Already in 1984, the Health Council advises to not take unnecessary precautions when caring for patients. This advice is described in the *SOA-Bulletin*: "*Unnecessary precautions, such as aprons, gloves, hats and mouth patches, where not strictly necessary, can make patients anxious.*"[95] It is interesting to read that, even though much is still unclear, it is already advised to not take too many precautions. Taking unnecessary precautions is how patients can feel stigmatized.

2.1.2 Transmission

It was still not completely clear how the virus would spread, however, some reliable information was already available.[96] During this period, it was feared that AIDS would spread fast and widely around the Netherlands. This also becomes clear in the articles. One article refers to the fast spread of the virus in the United States and the fear of that happening in the Netherlands.[97] From many of these articles, it becomes clear that not everything was known about the spread of the virus yet. Four articles refer to uncertainties surrounding the transmission. For example: "*It is plausible that the disease can be transmitted through blood and tissues and body products that may contain blood.*"[98] It is already certain that AIDS can be transmitted through blood, but not entirely sure how this would take place. Another article refers to the spread through semen: "*It now appears that we are dealing with a new infectious agent, perhaps a virus, which can be spread through blood and other bodily fluids, including semen.*"[99] Finally, one article describes anal sex as a risk-increasing factor: "*The role of anal contact as a risk-increasing factor is also controversial. It seems certain that it is not the only way through which AIDS is transmitted.*"[100]

There was already some information on how the virus can be transmitted. However, there are also still uncertainties. The last citation shows that even though it is known that AIDS is transmitted through other forms of sexual contact than just anal sex, it is not yet known through

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[95] Nationaal Archief, 2.19.225, I77, Archief van Stichting Aids Fonds – Soa Aids Nederland, de stichting STOP AIDS NOW! En de Stichting Werkmaatschappij Soa Aids en hun taakvoorgangers, Inventory Number 466, J. Kok, 'De verpleging van AIDS-patiënten', *SOA-Bulletin* 5:3 (1984) 10-12.

[96] Sandfort, 'Pragmatism and Consensus'.

[97] Nationaal Archief, 2.19.225, I77, Archief van Stichting Aids Fonds – Soa Aids Nederland, de stichting STOP AIDS NOW! En de Stichting Werkmaatschappij Soa Aids en hun taakvoorgangers, Inventory Number 466, R. Tielman, 'Het sociaal-wetenschappelijk onderzoek', *SOA-Bulletin* 5:4 (1984), 10.

[98] Kok, 'De verpleging van AIDS-patiënten', 10-12.

[99] Nationaal Archief, 2.19.225, I77, Archief van Stichting Aids Fonds – Soa Aids Nederland, de stichting STOP AIDS NOW! En de Stichting Werkmaatschappij Soa Aids en hun taakvoorgangers, Inventory Number 466, J. van Everdingen, 'AIDS (Acquired Immune Deficiency Syndrome)', *SOA-Bulletin* 4:2 (1983), 2-3.

[100] Nationaal Archief, 2.19.225, I77, Archief van Stichting Aids Fonds – Soa Aids Nederland, de stichting STOP AIDS NOW! En de Stichting Werkmaatschappij Soa Aids en hun taakvoorgangers, Inventory Number 466, J. van Wijngaarden, 'Voorlichtingscampagne AIDS', *SOA-Bulletin* 4:3 (1983) 16-17.

which forms of sexual contact. As expected, in these articles there was attention to the anxiety and fear that the virus spread and the way the virus could be transmitted.

2.1.3 Stigmatization

During this period, there was attention to the negative impact the AIDS epidemic had on the emancipation of homosexuals. One example of this is an article in which the humanitarian frame was identified*:*

> *The many information, whether coloured or not, in the press has a negative influence on the emancipation of the gay movement. This is reinforced by the discussion about whether or not the blood banks accept blood from donors who belong to the risk groups.*[101]

The regulations harm the homosexual community. Furthermore, even though the literature suggested that the media mostly published informative content, the information did have a negative influence.[102] The media is referred to in other articles as well:

> *There are also signs of exaggerated fear in the Netherlands. During information meetings, 'Indian stories' repeatedly come to the fore, which no longer have any connection with reality. Unfortunately, the media plays an important role in this by spreading incorrect or misunderstood information.*[103]

Even though the Dutch policy was aimed at consensus and trying to avoid stigmatization, the stories that appeared in the media could still have led to this. A third article also refers to this: "*Guilt can play a major role in AIDS patients. Blame about past lifestyle, which may be the cause of the disease. This can be reinforced by the sensational stories in the press.*"[104]

These articles indicate that a lot of misinformation was spread. In the literature, there is some mention of this, but it is mainly stressed that this did not happen often.[105]

2.2 The transition from period one to period two: 1986-1987

During the transition from period one to period two, fifteen relevant articles were identified. Again, all these articles were published in the *SOA-Bulletin* and a few of them stem from the column 'recent developments surrounding AIDS'. Similar to the start of period one, the

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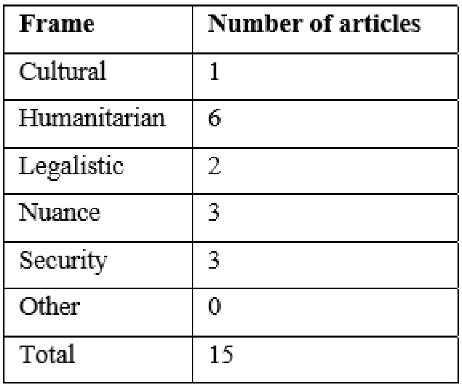
[101] Everdingen, 'AIDS', 2-3.
[102] Sandfort, 'Pragmatism and Consensus', 11-12.
[103] Wijngaarden, 'Voorlichtingscampagne AIDS', 16-17.
[104] Kok, 'De verpleging van AIDS-patiënten', 10-12.
[105] Sandfort, 'Pragmatism and Consensus', 11-12.

humanitarian frame was identified in most articles. However, multiple other frames were also identified. During 1986 and 1987 the focus of the AIDS policy shifted from risk groups only to the general public. It was still expected that AIDS would become widely spread under the population, even among the entire population.



Frame	**Number of articles**
Cultural	1
Humanitarian	6
Legalistic	2
Nuance	3
Security	3
Other	0
Total	15

Table 4. Number of articles per frame during the transmission from period one to two

2.2.1 Patient care and interest

The attention to patient care did not come forward often in this period. However, there was attention to the issue of testing. In two articles, the legalistic frame was identified. These articles both described the discussion surrounding testing for antibodies and put down the legal and ethical arguments against it, with a focus on the interest of those considering testing. The impact of testing HIV-positive was seen as too big to take a test.

2.2.2 Transmission

In this period, it had become clear that HIV could also be transmitted through other forms of sexual contact. However, in the articles found, it was clear that the fear of transmission was already less. In three articles, the nuance frame was identified. These articles all described that the spread of the virus would be less than expected. One article describes the risk of being infected by a needlestick injury.[106] According to this article, which describes new advice by the Health Council, the chance of getting affected by a needlestick injury is less than one percent.[107]

2.2.3 Stigmatization

There was still attention to the stigmatization of homosexuals. In six out of fifteen articles, the humanitarian frame was identified. Articles in which the humanitarian frame was found, plead

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[106] A needlestick injury occurs when a healthcare worker accidently stabs themselves with an infected needle.

[107] Nationaal Archief, 2.19.225, I77, Archief van Stichting Aids Fonds – Soa Aids Nederland, de stichting STOP AIDS NOW! En de Stichting Werkmaatschappij Soa Aids en hun taakvoorgangers, Inventory Number 469, J. van Wijngaarden, ‘Derde rapport Gezondheidsraad’, *SOA-Bulletin* 8:1 (1987), 10.

for better information in the media, ask for attention to the condition of AIDS patients and call for the prevention of stigmatization of homosexuals: "*The fact that AIDS in the Netherlands is currently mainly related to homosexuality complicates matters even further. The trepidation, secrecy, and ignorance of many people, including clinicians, regarding homosexual lifestyles, further increases the taboo against AIDS.*"[108] Another article states that the true "*epidemic lays in the mass hysteria*".[109] This mass hysteria is caused by misinformation spread by the media: "*Anyone who has followed the reporting on AIDS in newspapers and on radio and T.V. of the past three years will have noticed that the scope of the reporting does not always match the quality.*"[110] Another article states that it is expected that the knowledge on transmission will continue to grow and that this will take away much of the anxiety surrounding the virus.[111] Even though the literature stated that there was less spread of misinformation in the Netherlands than in other countries, these sources indicate that misinformation was spread by the mass media to some extent. Furthermore, according to these sources, there was a taboo on AIDS.

Even though the information campaign started targeting the general public, many articles still focussed on the spread among homosexuals. This could have led to the stigmatization of homosexuals. During this period, only one article described specific regulations on how to treat patients. This article was based on the advice given out by the Health Council and gave instructions on how to deal with a needlestick injury.

2.3 The transition from period two to three: 1990-1991

From this period, twenty articles were analysed. Five articles were published in the *SOA-Bulletin*, six articles in TvZ, and all other articles stem from *HIVNieuws*. The humanitarian frame was still dominant. During these years, it became clear that AIDS would not become as widely spread as was once feared. The expectation is that this will be visible in the sources and that there will be fewer articles on fear or media spreading misinformation since more information is already known.

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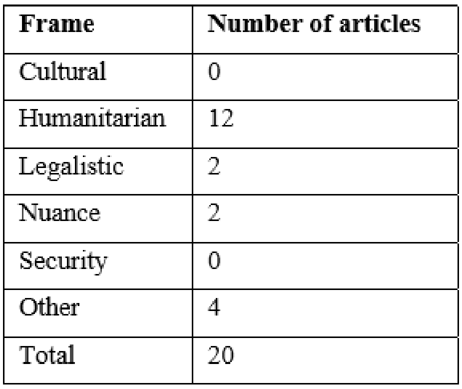
[108] Nationaal Archief, 2.19.225, I77, Archief van Stichting Aids Fonds – Soa Aids Nederland, de stichting STOP AIDS NOW! En de Stichting Werkmaatschappij Soa Aids en hun taakvoorgangers, Inventory Number 468, M. Paalman, 'AIDS: welke lessen kunnen uit de SOA-bestrijding gehaald worden', *SOA-Bulletin* 7:1 (1986), 4-6.

[109] Nationaal Archief, 2.19.225, I77, Archief van Stichting Aids Fonds – Soa Aids Nederland, de stichting STOP AIDS NOW! En de Stichting Werkmaatschappij Soa Aids en hun taakvoorgangers, Inventory Number 468, H. Moerkerk, 'Aids: voorlichting en preventie', *SOA-Bulletin* 7:3 (1986), 3-5.

[110] Ibidem.

[111] Nationaal Archief, 2.19.225, I77, Archief van Stichting Aids Fonds – Soa Aids Nederland, de stichting STOP AIDS NOW! En de Stichting Werkmaatschappij Soa Aids en hun taakvoorgangers, Inventory Number 468, J. van Wijngaarden, 'Recente ontwikkelingen rond AIDS', *SOA-Bulletin* 7:3 (1986), 7-8.



Frame	Number of articles
Cultural	0
Humanitarian	12
Legalistic	2
Nuance	2
Security	0
Other	4
Total	20

Table 5. Number of articles per frame during the transmission from period two to three

2.3.1 Patient care and interest

During this period, there was a lot of attention to patient care and interest. First, for the patients themselves, but also for the medical personnel treating them.

In the articles in which a humanitarian frame was identified, attention was asked to the psycho-social impact of being an AIDS patient. In the AMC a special department is opened for this, the National AIDS Therapy Evaluation Centre (NATEC). The HIV association emphasizes the interest of the patient.[112] Furthermore, there is attention to the creation of centre hospitals for AIDS patients. One of the arguments in favour of having hospitals that are specialized in AIDS care was that patients could find support from each other.[113]

Four articles have been given the label ‘other’. In these articles, no clear frame was identified. However, they are still interesting to take into consideration. Three articles are from *HIV Nieuws.* One article gives information on the benefits of home care and two articles describe different departments of the AMC. One is the dermatology department and the other is the dentistry department. The dentistry department mediates between dentists and HIV-positive persons if a dentist refuses to treat them.[114] Both the dentistry and the dermatology department indicate that they do not take extra precautions when treating HIV-positive patients. However, both do take more time to treat these patients and are extra careful: “*Gloves are worn for most procedures, but that is also the case for patients who are not infected with HIV. In general,*

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[112] HIV Vereniging, Department HIV Nieuws, Inventory Number 466, Tjerk Zweers, ‘NATEC geopend’, *hiv nieuwsbrief* 10 (1991), 3.

[113] Nationaal Archief, 2.19.225, I77, Archief van Stichting Aids Fonds – Soa Aids Nederland, de stichting STOP AIDS NOW! En de Stichting Werkmaatschappij Soa Aids en hun taakvoorgangers, Inventory Number 474, B.D.P. Eijrond, ‘Aids centrumziekenhuizen en verpleeghuizen’, *SOA-Bulletin* 12:3 (1991), 9-11.

[114] HIV Vereniging, Department HIV Nieuws, Inventory Number 466, Leendert Dros, ‘Tandheelkunde in het AMC’, *hiv nieuwsbrief* 10 (1991), 14.

work is done more carefully with HIV-infected people."[115] This extra time and extra carefulness should prevent accidents with cutting or needles from happening. Even though both departments declare not to take extra precautions, essentially taking extra time for these patients is also a precaution.

Five articles in which a humanitarian frame was identified, were about the nursing of AIDS patients. One article describes that some nurses refuse to care for AIDS patients, which is not allowed.[116] One article contains an interview with three different nurses. They describe the care for AIDS patients as heavy, because they know their patients will not survive.[117] One article describes an investigation done in three hospitals. The most important conclusion is that nurses are worried about being contaminated, but do not always follow the procedures: "*Perhaps most shocking is the conclusion that the attitude of nurses, like that of doctors, does not seem to deviate much from prejudices in the population.*"[118] Just like under the general public, unnecessary worry and fear are also present among healthcare workers.

2.3.2 Transmission

In this period, it was quite clear how HIV could be transmitted. However, in one article it is addressed that even though it was not proven yet, French kissing could most certainly not lead to transmission of the virus. This is interesting since the article was published in 1991. Even though it states that it is almost certain this could not lead to transmission, it was not completely certain during this time. The risk of transmission is also still present in other articles. One article also refers to the fact that nurses do not always follow the 'universal precaution'.[119] The universal precaution entails that all patients are treated as potential AIDS patients, to prevent contamination. This was an advice given out by the Health Council. Still, nurses are extra careful when they know or assume that someone is HIV-positive. This also indicated that the disease is not fully accepted. The article states that AIDS will not be limited to the risk groups: "*One will also have to take into account that it is a disease that can indeed happen to*

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[115] HIV Vereniging, Department HIV Nieuws, Inventory Number 467, Leendert Dros, 'Dermatologie in het AMC', *hiv nieuwsbrief* 10 (1991), 6.

[116] HIV Vereniging, Department HIV Nieuws, Inventory Number 464, Jeannette Kok, 'Thuiszorg voor mensen met AIDS', *hiv nieuwsbrief* 2 (1989/1990), 4.

[117] HIV Vereniging, Department HIV Nieuws, Basement archive, Theo Honig, 'De rouw van de hulpverlener', *HIV Nieuws* 39 (1996), 24-27.

[118] Universiteit Leiden, Waleaus Bibliotheek, H.N. Sno e.a., 'Attitude en Aids', *Tijdschrift voor Ziekenverpleging* 100:4 (1990), 114-117.

[119] Universiteit Leiden, Waleaus Bibliotheek, Toine de Graaf, 'Je kunt het niet bij één les of voorlichting houden', *Tijdschrift voor Ziekenverpleging* 100:4 (1990), 108-109.

anyone.”[120] During this period, public campaigns were also aimed at the general public instead of at risk groups.

A final article addresses healthcare workers that are HIV-positive. A protocol was set up that describes that they can perform their work under normal circumstances and do not need to take extra precautions.[121] This confirms that it was clear at this time that, under normal circumstances during work, HIV could not be transmitted.

2.3.3 Stigmatization

During this period, no articles were found on misinformation spread in the media or stigmatization occurring at that time. However, one article published in *TvZ* analysed articles published in the eighties in the *TvZ* on homosexuality. In the earlier articles, the author indicates that stigmatization was still visible. However, this changed during the years:

> *In the publications on AIDS, in particular, an important shift is taking place in thinking about homosexuality and for the first time, policy-based clarifications are made about dealing with homosexuality in the care provided by nurses. (..) It looks like nurses have become aware in a very short of the oppressed position in which homosexuals have been for years.*[122]

According to this article, one of the consequences of AIDS is that nurses are now more aware of the oppressed position homosexuals are in. The care for AIDS patients has led to more understanding of homosexuality in general under nurses.

As was expected, there was more attention to issues of care and treatment. The articles from *HIV Nieuws* were mainly aimed at investigating the kind of care patients could get. Furthermore, during this period there was more attention to nurses themselves. Even though more information on the transmission of the virus was already known, research showed that nurses were still worried.

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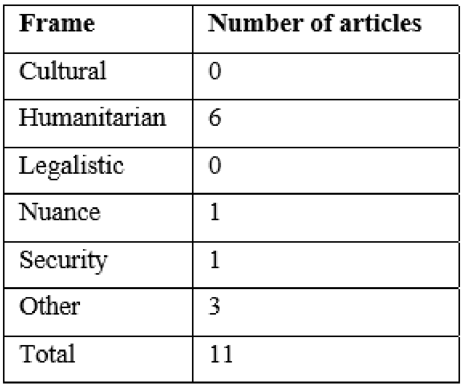
[120] Graaf, ‘Je kunt het niet bij één les of voorlichting houden’, 108-109.

[121] Nationaal Archief, 2.19.225, I77, Archief van Stichting Aids Fonds – Soa Aids Nederland, de stichting STOP AIDS NOW! En de Stichting Werkmaatschappij Soa Aids en hun taakvoorgangers, Inventory Number 474, B.D.P. Eijrond, A.N.M. Grunsven & L.L.F. Markenstein, ‘Vermeende HIV-infectierisico’s: gezondheidswerkers en tongzoenen’, *SOA-Bulletin* 12:4 (1991), 9-11.

[122] Universiteit Leiden, Waleaus Bibliotheek, H. Fleurke, ‘Van taboe naar beleid? (3)’, *Tijdschrift voor Ziekenverpleging* 100 (1990), 722-727.

2.4 The end of period 3: 1995-1996

In the years 1995 and 1996, eleven articles have been identified. In 1996, new medicines were brought on the market. It is expected that, during this period, fear and anxiety surrounding AIDS are less. Just as in the previous periods, the humanitarian frame remains dominant.



Frame	**Number of articles**
Cultural	0
Humanitarian	6
Legalistic	0
Nuance	1
Security	1
Other	3
Total	11

Table 6. Number of articles per frame at the end of period 3

2.4.1 Patient care and interest

The attention to patient care and interest is still divided into articles focussed on patients and articles focussed on healthcare personnel working with AIDS patients. In four articles, no frame was identified. Two of those articles advise AIDS patients. One article contained advice on how to prepare for a visit to the hospital.[123] Another article gives an overview of the benefits of home care.[124] A different article describes the optimism surrounding new medicines: "*For the first time in 15 years, more than false hope can be offered to people with HIV or AIDS.*"[125] The new challenge lies in motivating seemingly healthy people, that are HIV-positive but feel good, to take these medicines.

Other articles focus on the implications of working with AIDS patients. Two articles are about the role of nurses working with AIDS patients. One article describes the Congress of the American Association of Nurses in AIDS Care. During this congress, there was much attention on how heavy it could be to work in this field.[126] One article describes homosexual nurses that have chosen to work in the care of AIDS patients. Some of them turned out to be HIV-positive

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[123] HIV Vereniging, Department HIV Nieuws, Basement archive, Tineke van der Kruk, 'En, hoe was het op de poli?', *HIV Nieuws* 36 (1995), 20-22.

[124] HIV Vereniging, Department HIV Nieuws, Basement archive, HIV Vereniging, 'Dubbele blik op zorg', *HIV Nieuws* 37 (1995), 46-48.

[125] Universiteit Leiden, Waleaus Bibliotheek, Tineke van der Kruk, 'Het elfde wereld AIDS congres', *Tijdschrift voor Ziekenverpleging* 106:15 (1996), 707-709.

[126] Universiteit Leiden, Waleaus Bibliotheek, Klaas Hoeksema, 'Tijd voor heroriëntatie in Aidszorg', *Tijdschrift voor Ziekenverpleging* 105:16 (1995), 403-404.

themselves. According to the article, the occupational physician does not provide them with enough support.[127] A final article describes the process of preparing for euthanasia for nurses. This is mentally tough.[128] During this period, it was common for nurses to have to perform euthanasia on AIDS patients. In the eighties, almost a quarter of the Dutch AIDS patients had chosen euthanasia.[129]

From these articles, it becomes clear that besides attention to patients themselves, another important aspect of patient care is now the role of those caring for the patients, just like in the previous period.

2.4.2 Transmission

In this period, it had already become clear that AIDS would not spread as widely around the Netherlands. However, there were worries about the rest of the world. In one article, attention is given to Africa, where the virus is now rapidly spreading and medicines are not available to the general public.[130]

Two articles focus on the precautions that should be taken because of contagiousness. The security frame was identified in one source. This was an article inside an information leaflet of Aidsfonds. This article describes that there are still risks when working with AIDS patients. Nurses should make sure to be careful and to make sure to work hygienically.[131] In the other article, the nuance frame was identified. This article describes the precautions that should be taken when working with blood: wearing gloves and when there is a risk of blood-contaminated aerosols, a mask or goggles. The danger of contamination is part of the job: "*The dangers of blood-borne diseases are an occupational hazard that must be accepted to some extent*."[132]

Even at the end of period three, extra carefulness is still pressed. However, the second article shows that risks of contagiousness are part of a nurse's job in general.

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[127] Universiteit Leiden, Prof Dr J Mulder Bibliotheek, Theo Honig, 'HIV Fulltime: seropositieve verpleegkundigen in de Aidszorg', *Tijdschrift voor Ziekenverpleging* 106:23 (1996), 143-155.

[128] Universiteit Leiden, Prof Dr J Mulder Bibliotheek, Y.M. van der Brug, J. de Lange & H. Philipsen, 'Ervaringen van verpleegkundigen met euthanasie bij aids-patiënten', *Tijdschrift Verpleegkunde* 11:3 (1996), 143-155.

[129] Hageman, 'De opkomst van Aids', 67.

[130] Ibidem.

[131] Nationaal Archief, 2.19.225, I77, Archief van Stichting Aids Fonds – Soa Aids Nederland, de stichting STOP AIDS NOW! En de Stichting Werkmaatschappij Soa Aids en hun taakvoorgangers, Inventory Number 1258, Projectgroep Publiekscampagne AIDS/SOA, 'Hiv als beroepsrisico', *Informatiefolder: AIDS tussen negen en vijf en de gevolgen voor de werksituatie* (1995), 15.

[132] Universiteit Leiden, Waleaus Bibliotheek, Petra Nijdam, 'Prikaccidenten het melden waard', *Tijdschrift voor Ziekenverpleging* 106:17 (1996), 743.

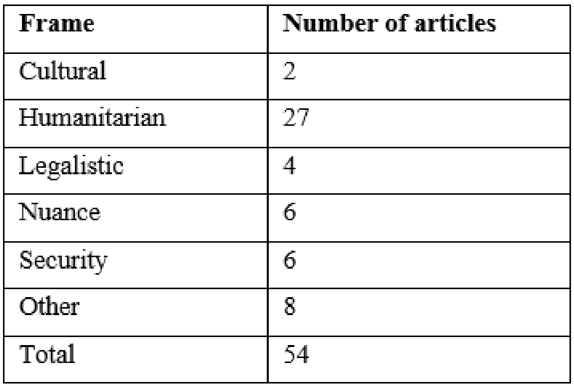
2.4.3 Stigmatization

There is less attention to stigmatization during this period. However, one article describes that there are still nurses who think that it is the patient's fault if they contracted AIDS. This could be of influence on their work:

> *Just as in society, there are also divergent views in our profession about what is and what is not permissible in the field of sexuality. Our vision often determines, consciously or unconsciously, verbally or non-verbally, our attitude towards the person who suffers from AIDS.*[133]

During this period, there was more attention to the impact of caring for AIDS patients for nurses and medical personnel in general. Furthermore, there was attention to the spread of AIDS in Africa. There was also optimism, due to the new medicines. However, one article showed that there were still nurses who were worried or had fear of treating these patients. This indicates that stigmatization of AIDS patients still occurred. Stigmatization of homosexuals did not come forward in this period.

2.5 Concluding remarks



Frame	Number of articles
Cultural	2
Humanitarian	27
Legalistic	4
Nuance	6
Security	6
Other	8
Total	54

Table 7. Total number of articles per frame

These sources have shown that healthcare personnel was informed of the risks of transmission of AIDS. Even though there were articles that described specific precautions, most articles did not discuss this. The humanitarian frame was dominant in all periods, but the content of these articles was different in each period. In the first period, the humanitarian articles mainly focussed on the stigmatization of homosexuals and the misinformation spread by the press. In the transmission from period one to period two, more attention is given to the support that AIDS

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[133] Universiteit Leiden, Waleaus Bibliotheek, Binjamin Heyl, 'Omgaan met zieken die lijden aan aids', *Tijdschrift voor Ziekenverpleging* 106: 13 (1996), 500-501.

patients need and how there is still a focus on homosexuals as risk groups, even though the virus could spread around the general public. In the transmission from period two to period three, much attention is given to the psycho-social aspect of care that AIDS patients need. The first articles on the impact of caring for these patients on the personnel also appeared. At the end of the third period, there is still attention to the needs of AIDS patients, but also the psychological impact on healthcare personnel. Furthermore, there is attention to the spread of AIDS in the rest of the world.

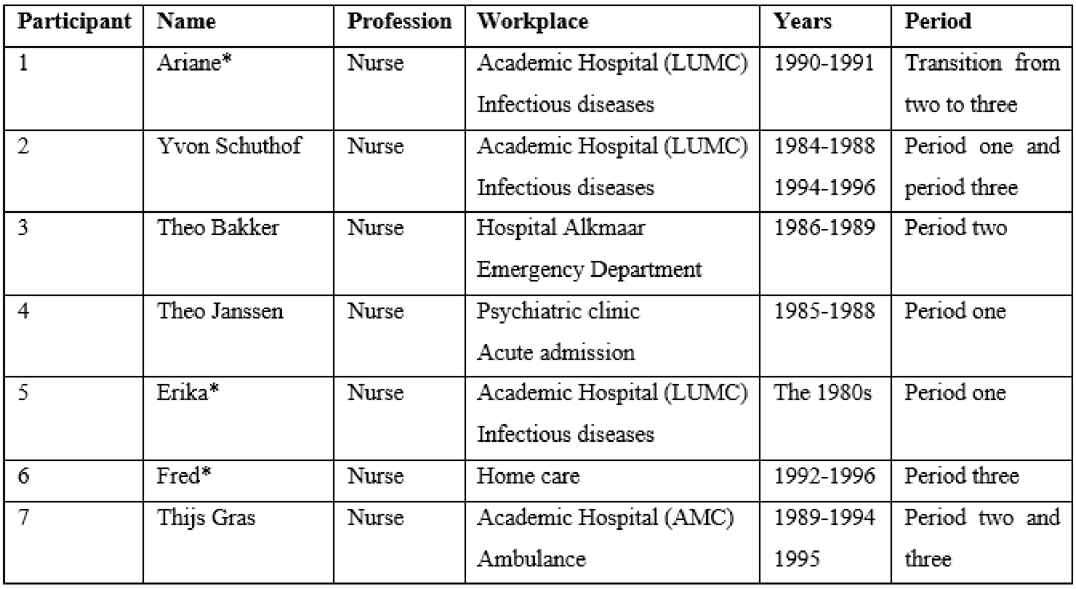
Attention to patient care and interest is present in all periods. First, this is focussed on the regulations that healthcare personnel should take, then on the impacts of testing HIV-positive, then on the psycho-social impact of being HIV-positive, and finally on the impact on healthcare personnel. Over time, there is less attention to the transmission. This can be easily explained by the fact that this information became simply known. During the first period, there were still uncertainties. However, even during that period ,there was some information, and healthcare personnel was already advised to not take unnecessary precautions. Already during the transition from period one to two, it became apparent that HIV was not as contagious as was thought before. There is attention to stigmatization in all periods. Both for AIDS patients, who were sometimes blamed for their status, and for homosexuals. During the start of the first period and the transmission from the first to the second, there is much attention to the media that spreads misinformation which could lead to stigmatization. This becomes less visible during the transmission from period two to three and at the end of period three.

According to Stutterheim, stigmatization takes place when unnecessary precautions are taken, a distance is being held, or when discomfort is felt. Already in the first period, one article made it clear which precautions were unnecessary and did not need to be taken. It can be assumed that these sources did not contribute to unnecessary precautions. There was mention of nurses feeling uncomfortable in their work, but this was discussed as an issue that needed to be solved. Therefore, it is not to be expected that these sources directly lead to unnecessary precautions, feeling uncomfortable, or keeping a distance.

As has become clear from these sources, there was no spread of disinformation toward healthcare personnel. However, in contrast to the literature, there was a spread of disinformation by the media. Already in 1984, healthcare personnel was asked not to take unnecessary precautions. In line with what was found in the literature, there was already some information on AIDS when the first patients were discovered. Nurses had the opportunity to be well-informed through magazines like *TvZ*. Finally, there was a lot of attention to homosexuality and the stigmatization of homosexuals. They were the main focus of these articles, even after 1986. This could have led to stigmatization.

Chapter 3: Experiences within their working environment

In this chapter, the experiences of healthcare staff within their working environment will be described and analysed. Within the theme of the working environment of healthcare staff, four sub-themes were discussed in all interviews. The first topic is the precautions that the participants had to take and how they were informed of this. The second topic is the conversations they had with their co-workers on the situation. The third topic is their experiences with patients. The final topic is fear and if they ever experienced fear themselves.



Participant	Name	Profession	Workplace	Years	Period
1	Ariane*	Nurse	Academic Hospital (LUMC) Infectious diseases	1990-1991	Transition from two to three
2	Yvon Schuthof	Nurse	Academic Hospital (LUMC) Infectious diseases	1984-1988 1994-1996	Period one and period three
3	Theo Bakker	Nurse	Hospital Alkmaar Emergency Department	1986-1989	Period two
4	Theo Janssen	Nurse	Psychiatric clinic Acute admission	1985-1988	Period one
5	Erika*	Nurse	Academic Hospital (LUMC) Infectious diseases	The 1980s	Period one
6	Fred*	Nurse	Home care	1992-1996	Period three
7	Thijs Gras	Nurse	Academic Hospital (AMC) Ambulance	1989-1994 1995	Period two and three

Table 8. Overview of participants[134]

The interviews were all held with nursing staff, working in different disciplines. Of the seven interviewed persons, six worked with at least one AIDS patient. Theo Janssen did not work with AIDS patients but does remember the discussion about precautions that needed to be taken.

3.1 Precautions

All interviewees were asked if they remembered having to take special precautions during this period. participants do remember clearly that instructions were different for working with AIDS patients, than with other patients. Yvon and Theo[135] recall that precautions taken in the

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[134] All names with an asterisk are pseudonyms. To protect the privacy of the participants, pseudonyms were made up for three participants. Furthermore, to distinguish between Theo Bakker and Theo Janssen, Theo Bakker will be referred to as 'Theo', while Theo Janssen will be referred to as 'Theo Janssen'.

[135] To distinguish between Theo Bakker and Theo Janssen, Theo Bakker will be referred to as 'Theo', while Theo Janssen will be referred to as 'Theo Janssen'.

beginning were very strict, later they were revised: "*In the beginning, they preferred to be as cautious as possible to protect their employees.*"[136]

Theo, who worked at the Emergency Department, described the extreme precautions taken at the beginning:

> *We were completely wrapped like Martians in hoods and suits and gloves, the gloves also had to be taped shut and everyone was very afraid when a patient with blood came. (...) especially because at the time we also knew how quickly you got infected [and if you did] then it was your death.*[137]

Theo worked at the Emergency Department during the start of period two. Even though there was already more known about how the virus was spread, precautions were still taken. This fear and the unknowingness about the spread of the disease led to precautions taken like being completely wrapped up when treating patients. In hindsight, it was completely unnecessary to be dressed this way. This also applied to the Psychiatric Clinic: "*Well, there were plans that we would have to walk around in full leather suits with leather gloves and goggles on and I thought it must be a serious illness.*"[138]

This shows that the precautions that were taken, or even being discussed, affected the way that healthcare personnel perceived the disease. Especially during the first period, it was not entirely clear how AIDS was transmitted. As has become clear from the literature and magazine articles, there was some knowledge on it, but there were still insecurities. Theo shares that this led to a lot of insecurity:

> *Especially if like the ambulance reported that there is blood in it and whether it was a nosebleed or if there was something of blood, everyone was very careful because they had the idea that probably is the way it is transmitted.*[139]

Quite early on, AIDS was suspected to be transmitted via blood. However, other ways of transmission were not excluded. It was clear that anal sex is a risk factor, but it was not yet sure what other forms of sexual contact are a risk. Because of this, healthcare workers were extremely cautious:

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[136] Yvon Schuthof, Oral history interview conducted by Roos Neven, 11 May 2022, online.

[137] Theo Bakker, Oral history interview conducted by Roos Neven, 13 May 2022, at Theo's current work.

[138] Theo Janssen, Oral history interview conducted by Roos Neven, 16 May 2022, online.

[139] Theo Bakker, Oral history interview.

> *If a patient had been there, everything had to be disinfected and cleaned. Because they were like what if it is conveyed differently. So a room where such a patient had been was completely cleaned before a new patient was brought in. You were always careful, but before the AIDS epidemic, we never worked with gloves. Only if it really had to be sterile.*[140]

In the citation above, extracted from the interview with Theo, it becomes clear that gloves were not usual to wear, until AIDS started spreading. This was also confirmed by Thijs:

> *Wearing gloves was a thing. I think we owe a lot to AIDS, that this became very common at some point. At first, you would have to get used to it a bit too. For example, when inserting IVs you were used to feeling the vein with your bare fingers. (...) Now on the ambulance, I'm very used to feeling veins through the rubber gloves. (...) Everyone now wears gloves as standard. I think that's something that was partly due to AIDS.*[141]

Both Theo and Thijs remember that gloves were introduced due to AIDS. Both of them worked with AIDS patients in period two, when more information was already known on the transmission of the virus. Even though it is now common to wear gloves with all patients, that was not the case when AIDS started spreading:

> *Before that, the use of gloves was not so common. Then it was just wipe someone's buttocks and wash your hands well. At the beginning of the education, this was also emphasized a lot, and techniques were taught to wash your hands properly. (...) That way you paid attention to hand hygiene, but you only wore gloves with AIDS patients or patients who had something contagious.*[142]

Thijs started working in the hospital in the second period. During this period, gloves became more common. As more information on the spread of the virus became known, precautions were adjusted, Theo shared:

> *Then [at the end] it got less. (...) The gloves stayed. The aprons got left behind at one point. But still, for example, splash goggles. We did that with all patients who we thought might have blood.*[143]

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[140] Theo Bakker, Oral history interview.
[141] Thijs Gras, Oral history interview conducted by Roos Neven on June 3, 2022, at Thijs' home.
[142] Ibidem.
[143] Theo Bakker, Oral history interview.

The extreme measures that had to be taken when Theo first worked with AIDS patients, got adjusted when more information on the spread of the virus became known, at the end of period two. This view was recognized by other participants, such as Ariane: "*You did that with all patients as soon as defecation was involved. Then you put on gloves. It was no different with AIDS patients.*"[144]

This citation by Ariane, who started working in the hospital during the transmission from period two to three, shows that eventually, gloves became usual to wear with all AIDS patients. Because at first gloves were usually only worn with patients that had AIDS or something else that was contagious, Thijs remembers that he and his colleagues liked to be warned before picking up an HIV-positive patient in the ambulance: "*We also liked to know if someone was HIV-positive. That was also information that made us alert to the situation and that made us always wear gloves.*"[145] This, again, indicates that the instructions or behaviour of nurses changed. Whereas Ariane remembers that gloves were always worn, Thijs remembers that, at first, they were only used with AIDS patients or patients with other infectious diseases.

Interestingly enough, Erika remembers that the hospital emphasized the well-being of the patients, instead of strict precautions that needed to be taken:

> *We were not asked if we wanted to [take extra precautions] so explicitly, because everyone knew that it was just not transferable through things. And yet I know that colleagues were very careful, but we were asked not to because it was simply proven that it was not contagious [through normal interactions]. (...) I don't know about other hospitals, but our doctors were aware of that. (...) I believe the hospital I worked in was progressive that those [stories on transmission] were bullshit stories.*[146]

The hospital Erika worked in, made sure to protect the psycho-social well-being of its patients. They made sure that nurses were well-informed on how the virus could be transmitted and did not believe in stories of transmission through, for example, shaking hands or drinking out of the same glass. Even though Erika worked here during periods one and two when special precautions were still taken in other hospitals, as has become clear from Theo's experience. The attention to psycho-social well-being of patients was also visible in the magazine articles, mainly during the transmission from period two to period three.

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[144] Ariane, Oral history interview.

[145] Thijs Gras, Oral history interview.

[146] Erika, Oral history interview conducted by Roos Neven, 16 May 2022, online.

Not only was the hospital very clear about what could and could not be contagious, but it also emphasized that the patients needed to be cared for well.[147] Thijs also remembers getting very clear instructions on the contagiousness of AIDS:

> *Actually, from the beginning, it was made clear, that though we feared AIDS, the chance that you will contract hepatitis was much higher. Because that is much more contagious and many more people have it. (...) Before you came to the ward you had to have your hepatitis vaccination.*[148]

Thijs was well instructed on the risks of caring for AIDS patients by the hospital. Not all participants remember this. Theo remembers mainly finding instructions that were spread by Aidsfonds.[149] Ariane and Fred do not remember the special precautions that had to be taken. Both of them worked with AIDS patients during the nineties, which was later than the other participants. Instructions for healthcare staff had already been reduced. Fred does not remember having to take special precautions but assumes that he could have found them somewhere. Ariane remembers being instructed on how to deal with bodily fluids, but not much more. Looking back, she wishes she had been involved more and had been explained more about what was safe and what was not:

> *No, we were not [involved in consultations] and there were no clinical lessons either. You got good instructions on how to deal with stools with blood and so on and that's why it wasn't scary because you knew exactly what you did was safe, but on the other hand, I think (...) that they also found it useful not to talk about it [to avoid fear among personnel].*[150]

During the period where Ariane worked at this department, she was also trying to get pregnant. She often carried a lot of pills and other medication that patients had to take and sometimes wondered whether that was safe in her position:

> *You sometimes walked with medicine cocktails (...)and certainly young women like me at that time who also wanted to get pregnant, there might be a little more [conversation on the risks of dealing with these medicines]well if you want to become pregnant and*

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[147] Erika, Oral history interview.

[148] Thijs Gras, Oral history interview.

[149] Theo Bakker, Oral history interview.

[150] Ariane, Oral history interview conducted by Roos Neven, 2 May 2022, online.

> *you walk in this department like this. What can that do to you [and] your body? Yes, shouldn't we have discussed that a bit more?*[151]

This shows that Ariane did not feel involved in the creation of precautions for dealing with medicines. She was not afraid of dealing with patients, but, looking back, she did feel uncomfortable with handling the medicine.

The above section shows that instructions differed greatly over the years. During periods one and two, multiple participants remember strict regulations. During period two, the use of gloves was introduced and nurses started to wear these with all patients, instead of just AIDS patients. Fred and Ariane do not remember special precautions. This aligns with the expectation that more information on the virus led to fewer precautions. The emphasis on the psycho-social well-being of the patients, as Erika experienced, shows that hospital staff did put an effort into avoiding the stigmatization of AIDS patients and certain groups. It will become clear in chapter four that, even though healthcare personnel gained more knowledge on the possible ways of transmission, misinformation was still spread among the general public by the media.

3.2 Conversations and fear among healthcare personnel

During all interviews, the topic of discussion among colleagues was brought up. All participants were asked whether or not they remember the care of AIDS patients to be a discussion point among them and their colleagues. They were asked whether their colleagues held a different opinion than them. All participants explained that they did have these discussions with their colleagues and all of them experienced that some of their colleagues were more afraid than themselves. In some cases, colleagues would refuse to work with AIDS patients:

> *Despite them being sick, they have to be helped and they're just people and so I've always said I don't care who comes. I help. But some colleagues simply refused to nurse AIDS patients, for example. Yes, they just said I don't do that. I think the risk is too great, I have children at home, I have a husband at home. I just don't. (...) And it was also allowed to refuse at that time. (...) But I thought it was actually against everything you want as a nurse or a doctor, that you want to help people and then say that you do not.*[152]

Some nurses simply refused to work with AIDS patients. This phenomenon of 'work refusers' was also discussed in *HIVNieuws.* According to that article, it is officially not allowed to refuse a patient, but nurses did try. Sometimes nurses would try to pass off work, instead of simply

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[151] Ariane, Oral history interview.
[152] Theo Bakker, Oral history interview.

refusing.[153] This article stems from 1990, so it is possible that refusing to care for certain patients stopped being allowed somewhere between 1986 and 1990. It could also be possible that the hospital in which Theo worked did still accept this. The sentiment shared here was also shared by Fred, who remembers the "*old guard*" of nurses at their work to be more afraid:

> *I did not think that was professional. That sounds very harsh, but then I thought you were a bit of a sucker. (...) Those old nurses were still doing things that we thought we knew or had figured out that we no longer had to.*[154]

Fred states that the older nurses would take extra precautions that were not necessary anymore. Fred refers to, what he calls, the "*emancipation of nurses*":

> *Until that time, the nurse did what they were being told and I think that the profession was like, hold on, we can decide for ourselves how to take care of patients.*[155]

In Fred's experience, nurses became more independent during this time. While reviewing articles in TvZ, many articles were aimed at this change. All nurses interviewed for this research were at the start of their careers during the spread of HIV. This could explain why they were more open to the emancipation of their profession and deciding what was safe or not, than the older healthcare staff. Theo Janssen noticed that, when precautions were discussed, some colleagues stated they would ask for a transfer to a different department.[156] Even though the participants did recall being well-informed on the risks of working with AIDS patients, some of their colleagues were still afraid to do so. This was visible in all three periods, even though Ariane experienced this less:

> *No, I thought it was in hindsight quite relaxed and that was of course also very nice, because those boys [in that period] it was still like AIDS was a bit your fault. (...) Sometimes parents came to visit who did not know what those boys had and so it was also nice that we as nursing staff could deal with it a bit relaxed.*[157]

The fact that Ariane did not experience any colleagues who thought of this differently, can be explained by the fact that she worked at the department later than the other participants. Ariane also refers to some people seeing AIDS as being the patients' fault, which was also mentioned

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[153] Jeannette Kok, 'Thuiszorg voor mensen met AIDS', 4.

[154] Fred, Oral history interview conducted by Roos Neven, 16 May 2022, at Fred's home.

[155] Ibidem.

[156] Theo Janssen, Oral history interview.

[157] Ariane, Oral history interview.

in the other sources. During the lectures with other nursing students, Ariane was often asked if she dared to visit the toilet at the department. Ariane feels that the atmosphere at the department led to her being more relaxed. Erika noticed that there were differences between herself and some colleagues:

> *Some people are a bit hypochondriac. One is more concerned than the other. The other is like you know, I work here I take care of this patient, and I (...) ensure that quality of care is delivered. I'm just going for it.*[158]

Erika noticed that some of her colleagues were more anxious about dealing with these patients. Fred observed that some staff still took unnecessary precautions, that they did not take when dealing with patients with other infectious diseases:

> *In the evening, that man also had to be visited and then he had to be prepared for the night. That meant that you could stop by and help him go to the toilet if necessary. Or that you [checked] if he needed a little washing, and people of the evening shift wanted the gloves to be by the front door, which of course is just chatter because AIDS is a disease where you have to be careful, but it doesn't have to be [that careful] and well, the night shifters never made a fuss [or inquired] when someone had hepatitis B or whatever, and then suddenly they did [make a fuss].*[159]

This shows that even though AIDS was not more contagious than hepatitis B, some colleagues still took extra, unnecessary precautions. Even when it was not clear whether a patient had AIDS, some healthcare workers were extra careful: "*For example when a woman came in, people were less panicky when a man came in. While that doesn't say anything at all*."[160] This shows that not only AIDS patients were stigmatized, but the risk groups were also too. This quote is from Theo, who worked at the Emergency Department during period two. During that time, the public prevention campaign was already aimed at the general public, while Theo's colleagues still were more careful when caring for a man. When more knowledge of the disease was gathered, the fear for these patients lessened. However, "*the prejudices remained*".[161]

Even though Thijs did not directly care for AIDS patients, he sometimes found out that a patient was seropositive afterward. This led to fear among co-workers:

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[158] Erika, Oral history interview.
[159] Fred, Oral history interview.
[160] Theo Bakker, Oral history interview.
[161] Ibidem.

> *And then gradually came the problem of (...)more and more people came who didn't have that diagnosis, but turned out to have it afterward, because of course it spread a bit. Someone who had another problem was also HIV-positive. So how did you deal with that? There was a bit of fear about that. So you started wearing gloves more often with people who did not have AIDS or paying extra attention that you did not come into contact or that you were extra careful with it.*[162]

All these stories show that, even though the participants themselves were well-informed on how to deal with these patients, some of their colleagues still led biases to lead their way of working. Multiple participants indicate that some of their colleagues did not want to treat AIDS patients. This was also visible in the primary sources, where it was discussed in multiple articles how there was also fear among nurses or how some nurses would find the contraction of AIDS the patient's fault. As has been shown in the literature, this was also visible in other countries. In the United States, the rise of homophobia occurred.

3.3 Direct patient contact

Participants were asked what they remembered about being in touch with these patients and what they experienced. For all of the participants, this was a memorable time and they could all describe their relationship with the patients they had to care for. Theo Janssen did not experience any AIDS patients during this period. Fred only experienced one AIDS patient. The other participants cared for multiple patients, some of them also in their personal sphere. This was especially the case for Theo, who was active in the gay scene and saw many acquaintances and friends be affected. Yvon remembers one patient vividly, a little boy:

> *I can remember one AIDS patient very well and that was a child, a boy. He came (...) from abroad. And he had a tumour on his face, but he also had AIDS. (...) And I remember very well that in the early days when AIDS came to the attention, the hospital struggled a lot with what is contagious and what is not contagious. As a nurse, how should you protect yourself and what should you wear. I remember well that we were packed, with coats and gloves and mouth masks and those things. Because we did not even know how contagious it was. And certainly, for such a little boy, who came from abroad, in a strange environment, people whose language he did not understand, who were then completely wrapped up, while he thought "I have cancer, that is not*

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[162] Thijs Gras, Oral history interview.

> *contagious", but he was contagious. (...) In retrospect, I can't blame the hospital for starting like this, with such rigorous measures.*[163]

Yvon remembers that she and her colleagues had to be completely wrapped up when caring for this patient, while the little boy did not understand why he was contagious. This was one of the first AIDS patients she remembers and she started working here in 1984. As became also visible in the magazine articles, between 1983 and 1984 there was already some information: the virus could spread through blood but also "*through other bodily fluids*".[164] This indicates there was still some uncertainty, which explains why the hospital took extra, unnecessary, precautions. Three participants recall not being able to share the diagnosis with the family or partner of the patient, at their wish:

> *I also know that we were faced with the fact that patients did not want that to be publicized, they had to have a different disease, especially if they were terminally ill, and it was not allowed to communicate to family members that they had the disease. And yes, some also had children. (...) A man had a son and he was not allowed to know because he had a shop here in Leiden. I will never forget it and he was just a tough guy. And, he said: 'you know, to me, it does not matter. You say, but my son will never be able to walk down the street again.'*[165]

Some people did not feel safe sharing their diagnosis because of the way it would reflect on their loved ones. The disease itself could still be a taboo. Yvon also remembers this: "*Even, and that's difficult, someone who was in a relationship with someone who didn't want their partner to find out that he had AIDS.*"[166]

However, this only occurred if it was the patient's wish to keep their disease hidden. The reasons that patients wanted to keep their condition private, were related to the taboo and stigma that surrounded AIDS.

3.4 Fear

All participants were asked whether they were afraid of working with AIDS patients. The answer, from all participants, was a firm no. Fred worked with one AIDS patient and even made sure he was able to take care of the patient because he found it an interesting case:

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[163] Yvon Schuthof, Oral history interview.
[164] J. van Everdingen, 'AIDS', 2-3.
[165] Theo Janssen, Oral history interview.
[166] Yvon Schuthof, Oral history interview.

> *When the indication [of what care a patient needed] had been made, we would receive the indications at the office, and then you (...) had to divide that up with each other, who will do what and I thought that was an interesting case, so I had (...) fished it out before we divided with each other, because, I thought it was interesting [and] a kind of unique situation.*[167]

Fred shared that there were not many AIDS patients in the village where he worked. This was the only patient that was cared for by them in the years he worked there. He, therefore, found it quite interesting to treat this patient. Two participants indicated that they stuck to the rules and, thus, were not afraid: "*if you just work neatly and follow all measures, then nothing has to be risky.*"[168] Thijs stated that it was always possible to contract one disease or another: "*In our work, you cannot avoid it, that is, of course, nursing work, that you are close to people and touch them and therefore also run the risk of contracting something.*"[169] This partially explains the matter of fact attitude all participants had. It was always possible to contract something at the workplace.

3.5 Concluding remarks

No participant remembers being afraid or not wanting to work with patients. However, some of their colleagues did. They remember finding this odd and being critical of this. This attitude was not according to the ethics of the work, according to some participants. In this chapter, it has become clear that, even though these participants were not afraid to work with AIDS patients and, mainly, felt well-informed, not all of their colleagues did. Theo noted that most information that reached them, was given out through the Aidsfonds, while Erika recalls being well-informed through the hospital itself. As will become clear in the next chapter, many participants also remember that information was spread through general media, but that this information could be misleading. This shows that experiences can greatly differ per person and hospital. Ariane and Fred mention not remembering having to take strict precautions or being well-informed. This could be explained by the fact that they started working in the field from the end of period two and the start of period three. In general, all participants, working with these patients for different periods, recall some colleagues still being very afraid of the transmission of the disease. However, the refusal of treating patients with AIDS was not mentioned by all participants. This could indicate that the fear of AIDS over time, was lessened,

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[167] Fred, Oral history interview.

[168] Erika, Oral history interview.

[169] Thijs Gras, Oral history interview.

as was also mentioned by Theo. This could simply be explained by the knowledge gained on the ways the virus could be transmitted. One thing the participants remember in particular is the patients that did not want to share their diagnosis with their family or loved ones. This could indicate that stigmatization of patients with the disease, was still large outside of the hospital.

As was stated at the beginning of this research, it is expected that the way healthcare workers were informed, had an impact on the stigmatization of homosexuals during the spread of HIV. However, as has become clear from the experiences of these nurses, stigmatization did happen among some healthcare workers, but this was not caused by the information that the hospital provided. Even though the rules were extremely strict at the beginning, participants understood this and thought it was good that they were cautious. Erika mentioned the psycho-social well-being of AIDS patients and that this was stressed by hospital management. This could lead to the conclusion that the information healthcare workers received did not lead to stigmatization.

Chapter 4: Experiences in the personal environment

In this chapter, the experiences of the participants in their personal environment will be discussed. The first theme is the thoughts of their personal environment, such as their friends and family, on their work and involvement with AIDS patients. The second theme is the difference between being a healthcare worker or not concerning feelings and thoughts on AIDS. The third theme is the stigmatization of homosexuals and AIDS patients.

4.1 Personal environment

All participants were asked what their friends and family thought of them working with AIDS patients and if they ever expressed their worry or fear. Erika, Fred, and Thijs do not remember this. However, Fred also admitted that he did not share much about his work and that he is not sure how many people in his environment knew that he worked with an AIDS patient. Ariane, Yvon, and Theo did experience getting mixed reactions from their friends and family. They were worried about the close contact they had with AIDS patients. From the experiences of the participants, it became immediately clear that their environment sometimes had a very different view of AIDS patients. This was the case for Ariane:

> *I was going to tell [my mother] very innocently and (...) because I also wanted to get pregnant that time(...) she said: 'Yes, but that is very dangerous' and [she called the patients] dirty boys.*[170]

This example shows that, while participants could be completely comfortable working with these patients and were all not afraid, their environment could think very differently. Yvon also experienced this, especially during the years she first worked with these patients, which was from 1984 onwards:

> *Well, certainly in the early years, when it was still so early and so little was known about it, I do know that there were indeed people in my environment who found it scary that I had to take care of AIDS patients.*[171]

Yvon's citation shows that the general public still was not aware of how the virus was transmitted during the first period. In Theo's case, his environment was not only afraid of him working with AIDS patients, but also warned him to be careful in everyday life. Theo was active in the gay scene, which caused his parents to worry for his safety even more:

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[170] Ariane, Oral history interview.

[171] Yvon Schuthof, Oral history interview.

> *Well, for example, my parents were very concerned and told me to take care (...) not only in terms of work but also in my social life people were afraid or concerned about whether I would be careful.*[172]

A few participants mentioned that their partner was not worried or afraid. However, for some healthcare workers, this was not the case, Theo recalls: "*When it was known that it was sexually transmitted, I heard from colleagues that their partner no longer wanted sex with them.*"[173] When asked why those colleagues would continue their work, even though their partners were so afraid, Theo answered: "*I think that's the drive of nurses. They often have so much passion for their profession that they have something like 'I will continue.'*".[174]

This quote gives a perfect explanation of why the participants would continue their work, even when their environment was afraid or did not agree. Even if not all participants experienced this worry from their environment, it is telling that three of them did. This shows that, outside the hospital, views on AIDS might have been very different. It is plausible that the general public got their information from certain media that still spread misinformation. Their fear indicates that they did not get their information through the hospital or the Aidsfonds. Instead, rumours about the spread of the virus were still present in the general public in period two. This was also confirmed by the articles discussed earlier.

4.2 Differences with non-healthcare personnel

To further assess whether there was a difference in the way people viewed AIDS, participants were asked whether they thought they had a different opinion or view on the virus because they worked with patients or because they worked in healthcare. Five of the participants answered that they did believe they viewed the virus differently. Fred stressed that they believed that they did indeed know more than an average person, but that there was also a difference between young and old healthcare workers.[175] The biggest difference between the participants and the general public was that they had access to more reliable information on the way the virus could be transmitted. Ariane remembers that the information in the hospital was extremely different from how the virus was portrayed in the media:

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[172] Theo Bakker, Oral history interview.

[173] Theo Bakker, Oral history interview.

[174] Theo Bakker, Oral history interview.

[175] Fred, Oral history interview.

> *What you [saw] in the media, that was all painted very black (...). And then afterward that is also logical because a lot of people died. What I don't think went well in the media is the story about [how you got] infected. They were quite hysterical about that.*[176]

Ariane worked in the hospital during the transition from period two to three. This shows that misinformation was still spread in the media. Other participants also shared this sentiment. Many people did not know how the disease could be spread and were extremely, and unnecessary, afraid: "*No, I think society made it more exciting because (...) if you sit on someone's toilet, you will get infected (...) that kind of nonsense stories.*"[177] This sentiment was also shared by Thijs:

> *The media was very hysterical about it and everything those patients touched was potentially contaminated. Well, we found out pretty quickly that that wasn't the case. If someone took a sip from a cup that you took, you should just treat it like a cup, but if you just wash that off, you couldn't get AIDS from it. So things like that were brought up in the training. That you handled it a bit normally, but extra careful. Especially with those excretions and blood.*[178]

Thijs worked in the hospital during periods two and three. He addresses that the situation was quite different in the hospital, where knowledge was available on how AIDS could be spread and, in the case of Erika, the psycho-social well-being of patients was stressed:

> *Yes, psycho-social well-being did play a very large and important role, and in those conversations that were held with these patients. I think they were the most important, because looking at the media, the hospital was a safe haven, wasn't it? And in the media, it was still that if you drank from the glass, you could get infected.*[179]

This citation shows that the media still spread untrue information about the transmission of the virus when more knowledge was already obtained within the hospital. This is also in line with the other primary sources. Theo tried to inform others of the way the disease spread and to make sure that they did not believe in the spread of AIDS through, for example, drinking out of the same cleaned cup:

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[176] Ariane, Oral history interview.

[177] Erika, Oral history interview.

[178] Thijs Gras, Oral history interview.

[179] Erika, Oral history interview.

> *I always try to tell people. It's okay, you know? You do not just get it and you do not get it from a cup of coffee that you get from someone else. Because some people, for example, [if an HIV-positive person visited them,] they would simply throw away the crockery. If you just wash the dishes, there is nothing wrong. You can't get it from the toilet seat or a cup.*[180]

Yvon agrees with the notion that the healthcare staff was better informed. She shares a memory of her own family, about her cousin that contracted AIDS:

> *I have a cousin who had haemophilia (...). Those blood products [that he was given] were obtained from France and during that period, blood was not yet screened for HIV in France. And so he was given contaminated blood, which caused him to contract AIDS.(...) I also know, within my family, an uncle of mine, when he heard that my cousin had AIDS, did not want him to come to visit and drink from a cup because he was afraid that if he drank from the cup my uncle might get AIDS from it.*[181]

All participants agree that their different opinion was due to the information they did receive and that other people either did not get or did not want to listen to. According to Erika: "*The unfamiliarity ensures that you are not properly informed. And then you keep a kind of backlog and that was also the case at that time*".[182]

Yvon's uncle was also not properly informed:

> *I think if you (...) see it up close or nurse people who have it, you look at it very differently than people who don't know very much about it. (...)That was also with that uncle of mine, he wasn't a nasty uncle at all, but he just didn't have enough knowledge.*[183]

As has become clear in chapter three, some patients decided not to share their diagnosis with their family or loved ones. This can easily be explained by the examples above, in which it becomes clear that the general public could be greatly misinformed about the way the virus was transmitted. Even when there was so much unrest and misinformation outside the hospital, the participants did not hesitate to care for these patients:

> *I always find that in healthcare (..) they are just people, it doesn't matter where they come from, what race, gender, or preference they have. They are people and I think you*

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[180] Theo Bakker, Oral history interview.

[181] Yvon Schuthof, Oral history interview.

[182] Erika, Oral history interview.

[183] Yvon Schuthof, Oral history interview.

> *should treat everyone equally. And I think that in the Netherlands, in general, that just happens.*[184]

The above section has shown that, even though much information was present within the hospital walls, it did not always reach the public. Especially because of media outings, many people were afraid of the spread of the virus and, especially during the first and even the second period, believed that AIDS could be spread through drinking out of the same cup, or sitting on the same toilet. All participants believed that they had a different view than other people because of the information they received and because they experienced the virus from up close.

4.3 Stigmatization

The literature has shown that homosexuals were the greatest risk group of contracting AIDS.[185] Five participants mentioned that they thought stigmatization of homosexuals took place. Theo experienced this up-close:

> *I was quite active in the gay scene myself and very quickly there was a rumour that something was going around that is just deadly and it happened especially in the gay world and (...) that is also a pressing stigma (...) you already have a stamp because you are gay and now we get another stamp that we are also the cause of a deadly virus.*[186]

This shows that the spread of AIDS led to another prejudice against homosexuals. The other participants mentioned that it was seen as a homosexual disease, for example, Fred: "*I think AIDS in those early days, was also a kind of disease for gays. That sounds a bit crude, but I don't know when that changed.*"[187] Yvon mentions the same: "*AIDS is a disease of homosexuals. That became a stigma. The gay scene, that's where it happened the most.*"[188] Erika recognized this as well: "*Yes it was always associated with homosexuality and men.*"[189] Thijs mentions not having been afraid of contracting AIDS because it was not "*such a hot item in heterosexual circles*".[190] This could also lead to different treatment of people who were, or who were thought to be, homosexual: "*AIDS started in the gay scene. So yes, even people you suspected were in that scene, you were a bit more careful with that.*"[191] These sentiments were

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[184] Theo Bakker, Oral history interview.
[185] Kok e.a., "Safe sex' and 'compassion'', 21.
[186] Theo Bakker, Oral history interview.
[187] Fred, Oral history interview.
[188] Yvon Schuthof, Oral history interview.
[189] Erika, Oral history interview.
[190] Thijs Gras, Oral history interview.
[191] Ibidem.

also shared by Theo, who recognized that other nurses were more careful when treating men than women. This had great consequences for homosexuals. Even though the Dutch AIDS policy was partly targeted at preventing stigmatization, this could not prevent severe discrimination, as Theo remembers:

> *At the time, for example, getting a mortgage with a bank well you could forget that. You didn't get your job, a permanent position. (...) Even if you came to the bank as a homosexual and that was known, it was very difficult to get a mortgage.*[192]

Even though the Netherlands was seen as a tolerant country, the stigmatization of homosexuals due to AIDS led to great disadvantages for them. This also happened in personal spheres. This was, for example, the case for the cousin of Yvon: "*My cousin had haemophilia and was also gay. My uncle was also very vehement that he had AIDS because he was gay. And that was not the case.*"[193] This shows that some AIDS patients, specifically homosexual patients, were blamed for contracting the disease. This was also visible in some of the articles, as mentioned in chapter two. Theo does remember that there was some publicity to prevent stigmatization. He remembers some campaigning that "*it was not just a gay disease*".[194] This probably occurred around the time Theo worked in the hospital himself. At this time, it had become clear that other people could also get infected.

Stigmatization also affected other population groups. Thijs worked in a hotel during his study, where often prostitutes would meet their clients: "*Both male and female. And we noticed that in the mid-1980s that market collapsed because people no longer wanted to have sex that way. (...) Also in that prostitute scene, that has had a huge impact.*"[195]

It has become clear that stigmatization of homosexuals did happen in the Netherlands, even though the policy was aimed at preventing this. Four of seven participants mentioned some form of AIDS being a "gay disease". All participants also mainly cared for young homosexual men. This could have strengthened their view of AIDS mainly being a disease for homosexuals. However, as mentioned above, this view was quite apparent in the entire Dutch society and not just within the hospitals.

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[192] Theo Bakker, Oral history interview.
[193] Yvon Schuthof, Oral history interview.
[194] Theo Bakker, Oral history interview.
[195] Thijs Gras, Oral history interview.

In other countries, the taboo on AIDS was even bigger than in the Netherlands, Ariane and Yvon agree. Yvon noticed this difference first-hand when she worked in Africa:

> *I went to Africa in 1997 to work there. There were, of course, many AIDS patients. Most of the patients in the hospital there had AIDS. So I saw a lot there. And of course, we looked at it very differently. (...) For example, if people died, it was never from AIDS. It was taboo to say you had AIDS.*[196]

Theo, Fred, and Thijs ascribe a possible difference to the Dutch mentality:

> *I think homosexuality was more accepted here than in other countries, so I can also imagine that that was the care for such a typical gay disease like AIDS (...)That is something we also have to offer. Or that is also something we need to know about. (...) But on the other hand, I also know that sometimes people thought a little too rosy about our acceptance rate.*[197]

So even though Fred thinks there might have been a difference, he immediately states that this might be too optimistic. Theo mentions something similar as typical for the Netherlands:

> *I think it was kind of the same, but in the Netherlands, we are a bit more "nuchter" [matter of fact] in terms of thinking. So we're more likely to be like, we have to deal with it. I haven't seen the hysteria you saw in America, for example. There people were on the street the next day, or they were fired.*[198]

There is no one clear answer to the question of whether or not the Dutch situation was different from other countries. The taboo in some countries or parts of the world was even bigger. This could be ascribed to the Dutch mentality of tolerance towards homosexuality, as the participants mention. However, stigmatization affected homosexuals in the Netherlands.

4.5 Concluding remarks

The aim of analysing these four themes was to discover whether or not there was a difference in the way healthcare personnel looked at AIDS and the general public looked at it. It has become clear that this difference existed to some extent. Not all participants remembered that their environment was worrying or scared for them working with AIDS patients, however, some of them did. Furthermore, Theo shared the extreme example of partners of nurses not wanting

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[196] Yvon Schuthof, Oral history interview.

[197] Fred, Oral history interview.

[198] Theo Bakker, Oral history interview.

to have sex with them, because of their fear of contracting AIDS. As was mentioned by multiple participants, misinformation was widely spread via the media. Participants mentioned that they had access to more and more accurate information and, therefore, were more aware of the dangers and possibilities of spreading. This could have led to less stigmatization among healthcare personnel. However, they did recognize the stigma that AIDS has put on homosexuality. AIDS was seen as a homosexual disease. The information gathered through the interviews has made it clear that there was a lot of stigmatization in the Netherlands. Due to the spread of false information, many people did not know how the virus could spread and were incorrectly careful. As was mentioned by Erika, some hospitals actively encouraged their personnel to not take these rumours seriously and to think of the psycho-social well-being of their patients.

In general, it can be stated that healthcare personnel had a different view on AIDS than some people in society. They were better informed and some of them actively tried to spread that information. Even though the rules were too precautious in the early years, participants indicate that they understand where this came from.

Chapter 5: Conclusion

It was announced only recently that regulations for homosexuals to donate blood would be further relaxed. The initial regulation, which was to ask homosexuals to withdraw from donating blood voluntarily, was made in 1983, during ‘bloody Sunday’. This was the official start of the AIDS policy in the Netherlands. Three periods can be distinguished in the Dutch AIDS policy. Period one lasted from 1983 until 1986. During this period, the National AIDS Policy Coordination Team was set up. During this period, the main discussion focussed on the contagiousness of the disease. As has become clear from both the interviews and the sources, not all information on the transmission of the disease was known yet. The second period was from 1987 until 1990. During this period, the NCAB took over the AIDS policy coordination and prevention activities stopped being solely aimed at risk groups. It was acknowledged that AIDS could be widely spread among the general public. Ethical and legal discussions were raised when the opportunity to test for HIV antibodies became available. More information on the transmission of HIV had become known, but misinformation was still spread in the media. The third period was from 1991 until 1996. In 1991 it was indicated that AIDS would not widely spread. During this period, there was more attention to issues of care and treatment for AIDS patients.

This research aimed to investigate whether stigmatization of homosexuals occurred during these periods. The research questions of this research were: “How did information on caring for AIDS patients handed out to healthcare personnel from 1983 until 1996 influence the stigmatization of homosexuals and how did nurses experience this period?” From this research, it has become clear that the information handed out to healthcare personnel was not the cause of, but did contribute to stigmatization. Nurses experienced to be well-informed and to have a different opinion than the general public. The first hypothesis was that these sources show little to no stigmatization of homosexuals. As was stated in the introduction, the creation of the AIDS policy was widely viewed as unique because of the involvement of risk groups and the focus on own responsibility. Since the Netherlands is also known as tolerant of homosexuals, it was expected that prejudices and stigmatization of homosexuals occurred less in the Netherlands than in other countries. However, it has become clear that stigmatization was certainly present in the Netherlands, mainly caused by the spread of misinformation. The second hypothesis was that rules and regulations become less strict and more positive as more is known about the contamination of HIV. This hypothesis has been proven true since strict regulations were managed during the first and second periods, whilst these were loosened in the third period.

The final hypothesis was that, once the first case of AIDS was found in the Netherlands, enough information about the spread of the disease was already known, so there was no communication of misinformation or extra precautions towards healthcare personnel. This, was expected, should have led to less stigmatization in the Netherlands than in other countries. However, even though there was some information on the spread of the disease, not all details were confirmed which led to extreme precautions still being taken. Furthermore, even though the Health Council advised against unnecessary precautions, these were still taken.

These conclusions were drawn by analysing a set of 54 articles from magazines aimed at nurses or medical health personnel and *HIVNieuws* and by conducting seven interviews with nurses. The magazine articles were analysed to identify whether this information could have led to stigmatization. As could have been expected from the periodisation, in these articles in period one there was attention to the contagiousness and transmission of AIDS, in period two there was attention to legal and ethical issues and in period three there was attention to issues with care and treatment. Even though the literature pointed out that there was little spread of misinformation, this was referred to in the sources. Furthermore, the attention to the spread of AIDS to the general public stayed limited. There was more attention to the spread among homosexuals. Even though the factors of stigmatization as Stutterheim described could not have been motivated by the articles in these magazines, the attention to the spread among homosexuals could have led to stigmatization. Finally, the articles in the first period indicated that there was already much information on the spread of HIV. Even though it is already known that it can be sexually transmitted and that anal sex is a risk factor, this has not been proven entirely. Therefore, unnecessary precautions were still taken in the hospitals, even though the advice from the Health Council was against this. The fact that these precautions were still taken, has become apparent from the interviews conducted with nurses.

Seven interviews with nurses were conducted. From these interviews, it became clear that there was a difference over time. While nurses working in the first period remembered that not much was known about the spread of the virus and had to be completely packed up when seeing patients, nurses working in period three do not remember having to take special precautions. It seems that the biggest change in these regulations occurred during the second period. From the interviews, it has become apparent that the introduction of wearing gloves occurred during this period. Where at first gloves were only worn with AIDS patients, it soon became normal to wear gloves with all patients. During the first period, the factors leading to stigmatization were present. However, as most participants also indicated, they do not know how they or the hospital could have acted differently since there was simply still so much unknown. This is somewhat in contrast with the primary sources, specifically with the Health Council advice from 1984. Most participants felt they were well-informed by their hospital. During period three, no special precautions were taken anymore. All participants felt they knew more about the virus than the regular population. They remembered misinformation being spread on the news and sometimes in their own families. They also remember that, while they had no fear of caring for AIDS patients, some colleagues did. Even though the literature indicated that there was little to no spread of misinformation, it has become clear that misinformation was spread.

Both the interviews and the magazine articles have shown that there was stigmatization of homosexuals and AIDS patients in the Netherlands. Even though the policy was aimed at preventing fear and spreading the right information, misinformation still reached the general public and sometimes nurses. Among all participants and in the magazines, there was attention for this. Participants do not remember getting wrong information from their hospital and in the magazines, there was also no spread of misinformation. Most participants remember the hospital being their main source of information. However, among the general public fear and misinformation on how the virus could be transmitted stayed apparent. In contrast to the available literature on AIDS policy in the Netherlands, strict regulations were still applied when nurses had contact with their patients during the first and second periods. Furthermore, there was more spread of misinformation than apparent in the literature so far. Finally, this thesis has contributed to the literature by giving nurses, who worked on the frontline during the epidemic, a voice. The experiences they shared have shed new light on the regulations of caring for AIDS patients and have shown how they were informed. Even though these nurses had the most patient contact, their experiences have been left out of research so far.

This research was conducted by analysing 54 articles and conducting seven interviews. The biggest recommendation for follow-up research would be to largen the data. Interviews are time-consuming but are a valuable addition to the literature. So far, the perspective of nurses had been neglected. Therefore, further research should continue to keep their perspective in mind. It would be interesting to compare the experiences of these Dutch nurses to the experiences of nurses in other countries. A comparison with, for example, nurses in the United States, could give insight into the difference between countries. Furthermore, it could be interesting to interview people that were afraid of treating AIDS patients.

The research questions of this research were: “How did information on caring for AIDS patients given to nurses from 1983 until 1996 influence the stigmatization of homosexuals and how did nurses experience this period?” It has become clear that stigmatization occurred in the Netherlands. Even though all participants felt they were well-informed about the virus, they had colleagues who were not. Both in the interviews and the magazines, the media was referred to as spreading misinformation. Furthermore, both in the interviews and in the magazines, AIDS was still mainly seen as a disease that occurred among homosexuals, even when public campaigns had diverted their attention to the general public. The Dutch policy was pragmatic and based on consensus, as stated many times before. However, this could not prevent stigmatization entirely. This is also visible in the rules regarding blood donations, only forty years after ‘bloody Sunday’, those changed from being based on whether a potential donor was homosexual or not to risk behaviour.

Bibliography

Literature:

Bauder, H., ‘Media discourse and the new German immigration law’, *Journal of Ethnic and Migration Studies 34,* 1 (2008) 95–112.

Blom, Cor, and Hospers, Harm, ‘HIV Prevention Activities for Gay Men in the Netherlands 1983-93’, in Theo Sandfort eds., *The Dutch response to HIV : pragmatism and consensus* (London 1998) 40-60.g

Boom, Frans van den, and Schnabel, Paul, ‘The Impact of AIDS on the Dutch Health Care System’, in Theo Sandfort eds., *The Dutch response to HIV : pragmatism and consensus* (London 1998) 153-174.

Brennan, L, ‘The battle against AIDS: a report from the nursing front’, *Nursing* 18 (1988) 60–64.

Bos, Arjan, Pryor, John, Reeder, Glen, and Stutterheim, Sarah, ‘Stigma: Advances in Theory and Research’, *Basic and Applied Social Psychology* 35:1 (2013) 1-9.

Carro, Jorge L, ‘From Constitutional Psychopathic Inferiority to AIDS: What Is in the Future for Homosexual Aliens?’, *Yale law & policy review* 7 (1989) 201–228.

Douglas C. J., Kalman C. M., and Kalman T. P. ‘Homophobia among physicians and nurses: an empirical study’, *Hospital Community Psychiatry* 36 (1985) 1309-1311.

Duyvendak, Jan Willem, and Koopmans, Ruud, ‘Weerstand bieden aan aids: de invloed van de homobeweging op aids-preventie’, *Mens en Maatschappij* 18:5 (1991) 237-245.

Dworkin, Joan, Albrecht, Gary, and Cooksey, Judith, ‘Concern about aids among hospital physicians, nurses and social workers’, *Social science & medicine* 33 (1991) 239–248.

Eakin, J. M., and Taylor, K.M., ‘The psychosocial impact of AIDS on health workers’, *AIDS* (4 (1990) 257–262.

Goffman, Erving, *Stigma: Notes on the Manaagement of Spoiled Identity* (New York 1986).

Hageman, Mariëlle, *Aids in Amsterdam* (Amsterdam 2018).

Hageman, Mariëlle, ‘De opkomst van aids’, *Historisch nieuwsblad : tweemaandelijks magazine over geschiedenis en het historisch bedrijf* 6 (2018).

Herek , G. M., ‘AIDS and stigma’, *American Behavioral Scientist* 42 (1999) 1106-1116.

‘Homomannen met vaste partner mogen bloeddonor worden’, *NOS* (March 11 2021).

Kok, Gerjo, Kolker, Lilian, Vroome, Ernest de, and Dijker, Anton, “Safe Sex’ and ‘Compassion’: Public Campaigns on AIDS in the Netherlands’, in Theo Sandfort eds., *The Dutch response to HIV : pragmatism and consensus* (London 1998) 19-39.

Kurzban, R., and Leary , M. R., ‘Evolutionary origins of stigmatization: The functions of social exclusion’, *Psychological Bulletin* 127 (2001) 187-208.

Leavy, Patricia, *Oral history* (New York 2011).

Mendicino, Thomas R., ‘Characterization and disease: homosexuals and the threat of AIDS’, *North Carolina law review* 66 (1987) 226-250.

Mooij, Annet, *Geen Paniek! AIDS in Nederland 1982-2004* (Houten 2004).

National Research Council, *The Social Impact of AIDS in the United States* (Washington D.C. 1993).

NOS, ‘Homomannen met vaste partner mogen bloeddonor worden’ (March 11 2021).

NOS, ‘Regels voor homoseksuele donoren verder versoepeld’ (May 25 2022).

Op de Coul, E.L.M., Beuker, R.J., Prins, M., Fennema, J.S., Meijden, W.I. van der, Coutinho, R.A., and Laar, M.J. van de, ‘HIV-infecties en AIDS in Nederland: prevalentie en incidentie, 1987-2002’, *Nederlands Tijdschrift voor Geneeskunde* 147:22 (2003) 1071-1076.

Phelan, J.C., Link , B.G., and Dovidio, J.F., ‘Stigma and prejudice: One animal or two?’ *Social Science and Medicine* 67 (2008) 358-367.

Sandfort, Theo, *Lesbian and gay studies : an introductory, interdisciplinary approach* (London 2000).

Sandfort, Theo, ‘Pragmatism and Consensus’ in Idem, *The Dutch response to HIV : pragmatism and consensus* (London 1998) 3-19.

Sandfort, Theo, Kerkhof, Marty van, and Zwart, Onno de, ‘No Anal Sex Please: We’re Dutch. A Dilemma in HIV Prevention Directed at Gay Men’, in Theo Sandfort eds., *The Dutch response to HIV : pragmatism and consensus* (London 1998) 135-152.

Schalkwijk, Hugo, and Lalleman, Pieterbas, ‘Van Krim tot Corona’, *Impact Magazine* 1 (2021) 34-37.

Schinkel, Willem, and Schrover, Marlou, ‘Introduction: The language of inclusion and exclusion in the context of immigration and integration’, *Ethnic and Racial Studies* 36 (2013) 1123-1141.

Schrover, Marlou, and Kampman, Frerik, ‘'Charter flights full of homosexuals'. The Changing Rights of Homosexual Immigrants in The Netherlands, 1945-1992’, *Tijdschrift voor sociale en economische geschiedenis* 16 (2020) 5-36.

Schrover, Marlou, ‘Problematisation and particularisation: The Bertha Hertogh story’, *Tijdschrift voor Sociale en Economische Geschiedenis* 8 (2011) 3–31.

Schrover, Marlou, and Walaardt, Tycho, ‘The Influence of the Media on Policies in Practice: Hungarian Refugee Resettlement in the Netherlands in 1956’, *Journal of Migration History* 3 (2017) 22–53.

Sontag, Susan, *Aids and its metaphors* (New York 1989).

Stutterheim, Sarah E., Bos, Arjan E.R., Pryor, John B., Brands, Ronald, Liebregts, Maartje, and Schaalman, Herman P., ‘Psychological and social correlates of HIV status disclosure: The significance of stigma visibility’, *AIDS education and prevention* 23:4 (2011) 382–392.

Stutterheim, Sarah, Kuijpers, Kyran, Waldén, Moon, Finkenflügel, Renee, Brokx, Pieter, and Bos, Arjan, ‘Trends in HIV Stigma Experienced by People Living with HIV in the Netherlands: A Comparison of Cross-Sectional Surveys Over Time’, *AIDS Weekly* 34:1 (2021) 55.

Tielman, Rob, *Homoseksualiteit in Nederland : studie van een emancipatiebeweging* (Meppel 1982).

Treiber, F.A., Shaw, D., and Malcolm, R., Acquired immune deficiency syndrome: psychological impact on health personnel, *Journal of Nervous and Mental Disease* 175:8 (1987) 496-499.

Veenker, Janherman, ‘The Decisive Role of Politics: Aids Control in the Netherlands’, in Theo Sandfort eds., *The Dutch response to HIV : pragmatism and consensus* (London, 1998) 121-134.

Yow, Valerie Raleigh, *Recording oral history: a guide for the humanities and social sciences* (Third edition; New York 2015).

List of primary sources:

Nationaal Archief, 2.19.225, I77, Archief van Stichting Aids Fonds – Soa Aids Nederland, de stichting STOP AIDS NOW! En de Stichting Werkmaatschappij Soa Aids en hun taakvoorgangers, Inventory Number 36

SOA Stichting, Jaarverslag 1983, 1984.

SOA Stichting, Jaarverslag 1984, 1985.

Nationaal Archief, 2.19.225, I77, Archief van Stichting Aids Fonds – Soa Aids Nederland, de stichting STOP AIDS NOW! En de Stichting Werkmaatschappij Soa Aids en hun taakvoorgangers, Inventory Number 43

SOA Stichting, Jaarverslag 1991, 1992.

Nationaal Archief, 2.19.225, I77, Archief van Stichting Aids Fonds – Soa Aids Nederland, de stichting STOP AIDS NOW! En de Stichting Werkmaatschappij Soa Aids en hun taakvoorgangers, Inventory Number 466

SOA Stichting, ‘Waarom dit Bulletin SOA?’, *SOA-Bulletin* 1:1 (1979), 1.

Everdingen, J. van, ‘AIDS (Acquired Immune Deficiency Syndrome)’, *SOA-Bulletin* 4:2 (1983), 2-3.

Wijngaarden, J. van, ‘Voorlichtingscampagne AIDS’, *SOA-Bulletin* 4:3 (1983), 16-17.

Wijngaarden, J. van, ‘Recente ontwikkelingen rond AIDS’, *SOA-Bulletin* 5:1 (1984), 7-8.

Wijngaarden, J. van, ‘Recente ontwikkelingen rond AIDS’, *SOA-Bulletin* 5:2 (1984), 12-13.

Wijngaarden, J. van, ‘Recente ontwikkelingen rond AIDS’, *SOA-Bulletin* 5:3 (1984), 13.

Kok, J., ‘De verpleging van AIDS-patiënten’, *SOA-Bulletin* 5:3 (1984), 10-12.

Tielman, R., ‘Het sociaal-wetenschappelijk onderzoek’, *SOA-Bulletin* 5:4 (1984), 10.

Wijngaarden, J. van, ‘Recente ontwikkelingen rond AIDS’, *SOA-Bulletin* 5:4, 16-17.

Nationaal Archief, 2.19.225, I77, Archief van Stichting Aids Fonds – Soa Aids Nederland, de stichting STOP AIDS NOW! En de Stichting Werkmaatschappij Soa Aids en hun taakvoorgangers, Inventory Number 468

Paalman, M., ‘AIDS: welke lessen kunnen uit de SOA-bestrijding getrokken worden?’, *SOA-Bulletin* 7:1 (1986), 4-6.

Paalman, M., ‘Symposium AIDS’, *SOA-Bulletin* 7:1 (1986), 9.

Kok, J., ‘De hulpverlening en de psychosociale problemen rond AIDS’, *SOA-Bulletin* 7:1 (1986), 10-13.

Tielman, R., ‘Eerste resultaten psychosociaal AIDS-onderzoek’, *SOA-Bulletin* 7:1 (1986), 15.

Wijngaarden, J. van, ‘Recente ontwikkelingen rond AIDS’, *SOA-Bulletin* 7:2 (1986), 7-8.

Moerkerk, H., ‘Aids: voorlichting en preventie’, *SOA-Bulletin* 7:3 (1986), 3-5.

Wijngaarden, J. van, ‘Recente ontwikkelingen rond AIDS’, *SOA-Bulletin* 7:3 (1986), 9-10.

Wolf, F. de, Coutinho, R., Goudsmit, J., Krone, W., Schellekens, P., Danner, S., Griensven, G.J.P., van, Rijsdijk, T. & Noordaa, J. van der, ‘Infectie met HIV onder homosexuele mannen: prevalentie, incidentie en risicofactoren’, *SOA-Bulletin* 7:5 (1986), 11-12.

Wijngaarden, J. van, ‘Hoeveel prioriteit heeft de bestrijding van AIDS?’, *SOA-Bulletin* 7:6 (1986), 11-12.

Nationaal Archief, 2.19.225, I77, Archief van Stichting Aids Fonds – Soa Aids Nederland, de stichting STOP AIDS NOW! En de Stichting Werkmaatschappij Soa Aids en hun taakvoorgangers, Inventory Number 469

Zeijl, W.L.G. van, ‘Homosexualiteit en geneeskunde’, *SOA-Bulletin* 8:1 (1987), 7-8.

Wijngaarden, J. van, ‘Derde rapport Gezondheidsraad’, *SOA-Bulletin* 8:1 (1987), 10.

Wijngaarden, J. van, ‘Voorlichting over aids: de bijdrage van (huis)artsen’, *SOA-Bulletin* 8:2 (1987), 3-4.

Wijngaarden, J. van, ‘Aids, Washington 1987’, *SOA-Bulletin* 8:3 (1987), 3-4.

Tielman, R., ‘Preventie van aids onder mannen met homosexuele contacten’, *SOA-Bulletin* 8:3 (1987), 5-7.

Wijngaarden, J. van, ‘Serologisch onderzoek op antistoffen tegen HIV: tussenbalans van het ‘testbeleid’’, *SOA-Bulletin* 8:4 (1987), 8-9.

Nationaal Archief, 2.19.225, I77, Archief van Stichting Aids Fonds – Soa Aids Nederland, de stichting STOP AIDS NOW! En de Stichting Werkmaatschappij Soa Aids en hun taakvoorgangers, Inventory Number 473

Reus, J., & Sibeijn, M., ‘Vragen over aids in de huisartsenpraktijk’, *SOA-Bulletin* 11:2 (1990), 6-7.

Vlasblom, R.P., ‘Waarschuwen van partners bij HIV-infectie’, *SOA-Bulletin* 11:3 (1990), 6-8.

Eijrond, B.D.P. & Beckers, M.C.B., ‘Vroegtijdige medische interventie bij HIV-infecties’, *SOA-Bulletin* 11:5 (1990), 3-4.

Nationaal Archief, 2.19.225, I77, Archief van Stichting Aids Fonds – Soa Aids Nederland, de stichting STOP AIDS NOW! En de Stichting Werkmaatschappij Soa Aids en hun taakvoorgangers, Inventory Number 474

Eijrond, B.D.P., ‘Aids centrumziekenhuizen en verpleeghuizen’, *SOA-Bulletin* 12:3 (1991), 5-6.

Eijrond, B.D.P., Grunsven, A.N.M. & Markenstein, L.L.F., ‘Vermeende HIV-infectierisico’s: gezondheidswerkers en tongzoenen’, *SOA-Bulletin* 12:4 (1991), 9-11.

Nationaal Archief, 2.19.225, I77, Archief van Stichting Aids Fonds – Soa Aids Nederland, de stichting STOP AIDS NOW! En de Stichting Werkmaatschappij Soa Aids en hun taakvoorgangers, Inventory Number 1258

Projectgroep Publiekscampagne AIDS/SOA, ‘Hiv als beroepsrisico’, *Informatiefolder: AIDS tussen negen en vijf en de gevolgen voor de werksituatie* (1995), 15.

Nationaal Archief, 2.21.377, C51, Archief van Stichting Aids Fonds – Soa Aids Nederland, de stichting STOP AIDS NOW! En de Stichting Werkmaatschappij Soa Aids en hun taakvoorgangers, Inventory Number 1002

Wolters-Noordhoff BV, Voorbereidingsgroep Tijdschrift voor Verpleegkunde, 25th of September 1985

Nationaal Archief, 2.19.225, I77, Archief van Stichting Aids Fonds – Soa Aids Nederland, de stichting STOP AIDS NOW! En de Stichting Werkmaatschappij Soa Aids en hun taakvoorgangers, Inventory Number 71

SOA Stichting, ‘De SOA Stichting (in 1993 en 1994)’, Bijdrage aan het jaarboek 1993/1994 van de Nederlandse vereniging voor Dermatologie en Venereologie en de ‘Commissie-Marathon’ van de NVDV, 1.

HIV Vereniging, Department HIV Nieuws, Inventory Number 464

HIV Vereniging, n.t., *hiv nieuwsbrief* 1 (1989), 1.

Linden, Joop van der, ‘Bundeling van krachten’, *hiv nieuwsbrief* 1 (1989), 3.

Greef, Henk de, ‘Begrensde mogelijkheden’, *hiv nieuwsbrief* 1 (1989), 4-5.

Kok, Jeannette, ‘Thuiszorg voor mensen met AIDS’, *hiv nieuwsbrief* 2 (1989), 4.

Haan, Jan, ‘Trial unit in het AMC’, *hiv nieuwsbrief* 2 (1989), 10-11.

HIV Vereniging, Department HIV Nieuws, Inventory Number 465

Dros, Leendert, ‘Aidsconsulenten in het AMC’, *hiv nieuwsbrief* 6 (1990), 16-17.

HIV Vereniging, Department HIV Nieuws, Inventory Number 466

Zweers, Tjerk, ‘NATEC geopend’, *hiv nieuwsbrief* 8 (1991), 3.

Dros, Leendert, ‘Tandheelkunde in het AMC’, *hiv nieuwsbrief* 9 (1991), 14.

HIV Vereniging, Department HIV Nieuws, Inventory Number 467

Berg, Han van der, ‘Aktie in Rotterdam’, *hiv nieuwsbrief* 10 (1991), 3.

Dros, Leendert, ‘Dermatologie in het AMC’, *hiv nieuwsbrief* 10 (1991), 6.

Mostert, Henry, ‘Thuiszorg’, *hiv nieuwsbrief* 12 (1991), 7-8.

HIV Vereniging, Department HIV Nieuws, Basement archive

Kruk, Tineke van der, ‘En, hoe was het op de poli?’, *HIV Nieuws* 36 (1995), 20-22.

HIV Vereniging, ‘Dubbele blik op zorg’, *HIV Nieuws* 37 (1995), 46-48.

Honig, Theo, ‘De rouw van de hulpverlener’, *HIV Nieuws* 39 (1996), 24-27.

Universiteit Leiden, Waleaus Bibliotheek

Graaf, Toine de, ‘Je kunt het niet bij één les of voorlichting laten’, *Tijdschrift voor Ziekenverpleging* 100:4 (1990), 108-109.

Sno, H.N. e.a., ‘Attitutde en Aids’, *Tijdschrift voor Ziekenverpleging* 100:4 (1990), 114-117.

‘Individuele besluitvorming rond het testen op antistoffen tegen HIV’, *Tijdschrift voor Ziekenverpleging* 100:4 (1990), 166-168.

Fleurke, H., ‘Van taboe naar beleid? (3)’, *Tijdschrift voor Ziekenverpleging* 100:5 (1990), 722-727.

Kruk, Tineke van der, ‘AIDS: meer dan één ziekte’, *Tijdschrift voor Ziekenverpleging* 100:22 (1990), 47-49.

Müller-Koster, N., ‘De AIDS-patiënt in het verpleeghuis’, *Tijdschrift voor Ziekenverpleging* 101:4 (1991), 126-128.

Hoeksema, Klaas, ‘Lachen en huilen om aids’, *Tijdschrift voor Ziekenverpleging* 105:2 (1995), 401.

‘Afleiding als aidsremmer’, *Tijdschrift voor Ziekenverpleging* 105:7 (1995), 483.

Hoeksema, Klaas, ‘Tijd voor heroriëntatie in Aidszorg’, *Tijdschrift voor Ziekenverpleging* 105:16 (1995), 403-404.

Koppelaars, M.J.M., Lier, M.H.M., van & Mast, R.C., van der, ‘Psychiatrische stoornissen bij HIV-infectie’, *Tijdschrift voor Ziekenverpleging* 106:7 (1996), 454-455.

Heyl, Benjamin, ‘Omgaan met zieken die lijden aan aids’, *Tijdschrift voor Ziekenverpleging* 106:13/14 (1996), 500-501.

Kruk, Tineke van der, ‘Het elfde wereld AIDS congres’, *Tijdschrift voor Ziekenverpleging* 106:15 (1996), 707-709.

Nijdam, Petra, ‘Prikaccidenten het melden waard’, *Tijdschrift voor Ziekenverpleging* 106:17 (1996), 743.

Universiteit Leiden, Prof Dr J Mulder Bibliotheek

Honig, Theo, ‘HIV Fulltime: seropositieve verpleegkundigen in de Aidszorg’, *Tijdschrift voor Ziekenverpleging* 106:23 (1996), 143-155.

Brug, Y.M. van der, Lange, J. de & Philipsen, H., ‘Ervaringen van verpleegkundigen met euthanasie bij aids-patiënten’, *Tijdschrift voor Verpleegkunde* 11:3 (1996), 143-155.

Interviewed persons:

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Bakker, Theo, Oral history interview conducted by Roos Neven, 13 May 2022, at Theo’s current work.
Gras, Thijs, Oral history interview conducted by Roos Neven on June 3, 2022, at Thijs’ home.
Janssen, Theo, Oral history interview conducted by Roos Neven, 16 May 2022, online.
Schuthof, Yvon, Oral history interview conducted by Roos Neven, 11 May 2022, online.
Ariane, Oral history interview conducted by Roos Neven, 2 May 2022, online.
Erika, Oral history interview conducted by Roos Neven, 16 May 2022, online.
Fred, Oral history interview conducted by Roos Neven, 16 May 2022, at Fred’s home

Appendixes

List of themes and questions asked during interviews
Themes: remembrance of specific instructions, thoughts of environment, comparison to other countries, remembred experiences

Question list:

1. Toelichting onderzoek
2. Toestemming het interview op te nemen
3. Zou u zich kunnen voorstellen?
4. Ik heb via via vernomen dat u in de medische sector werkte ten tijde van het uitbreken van de aids pandemie, wat was precies uw rol?
5. Wat heeft u daarvoor gestudeerd/waar bent u naar school gegaan?
6. Van wanneer tot wanneer heeft u dat geTheo Janssen?
7. Kan je je het moment dat u voor het eerst over aids hoorde nog herinneren? Zo ja, wat ging er toen door u heen?
8. Wat voor instructies kregen jullie, bijv over het aanraken van patiënten?
    a. Veranderden die instructies door de jaren heen?
    b. Hoe hadden die vorm? Werden er bijvoorbeeld flyers verspreid?
    c. Zou u die nog terug kunnen vinden of weet u van welke organisatie die kwamen?
9. Heeft u wel eens contact met een AIDS patiënt gehad?
    a. Zou je die situatie kunnen omschrijven?
    b. Is die persoon uiteindelijk overleden?
    c. Hoe verliep het contact met die persoon?
    d. Wat vond uw omgeving daarvan?
    e. Welke specifieke instructies kreeg u hierbij?
    f. Heeft u meerdere contacten gehad?
10. Merkte u dat mensen in jouw omgeving voordelen hadden over je werk/aids patiënten?
    a. Veranderden die op een gegeven moment?
    b. Waardoor?
11. Hoe kijkt u achteraf terug op wat u heeft meegemaakt?
12. Denkt u dat de situatie in Nederland voor zorgpersoneel anders was dan in andere landen?
    a. Hoe komt dat?
13. Denkt u dat u anders dacht over het virus dan uw omgeving, omdat u er direct mee in aanraking kwam?
14. Kent u nog andere mensen die misschien beschikbaar zouden zijn om te interviewen?