

The background of the cover features a stylized illustration. At the top, there are white silhouettes of industrial buildings with smokestacks. In front of these, several red human figures are standing. Below the industrial scene, there are white silhouettes of multi-story office buildings, some with the letter 'H' on top. More red human figures are positioned in front of these buildings. To the right, there are red silhouettes of firefighters. The bottom section of the cover is filled with large, overlapping yellow circles. Some of these circles contain faint, light-colored icons: a hand pointing, a person with a cross, and a person with a heart. The overall color palette consists of white, red, yellow, and light blue.

# LIVING WITH HIV

Implications for  
work participation

MARLIES N. WAGENER

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# **LIVING WITH HIV:** Implications for work participation

# **LEVEN MET HIV:** Implicaties voor arbeidsparticipatie

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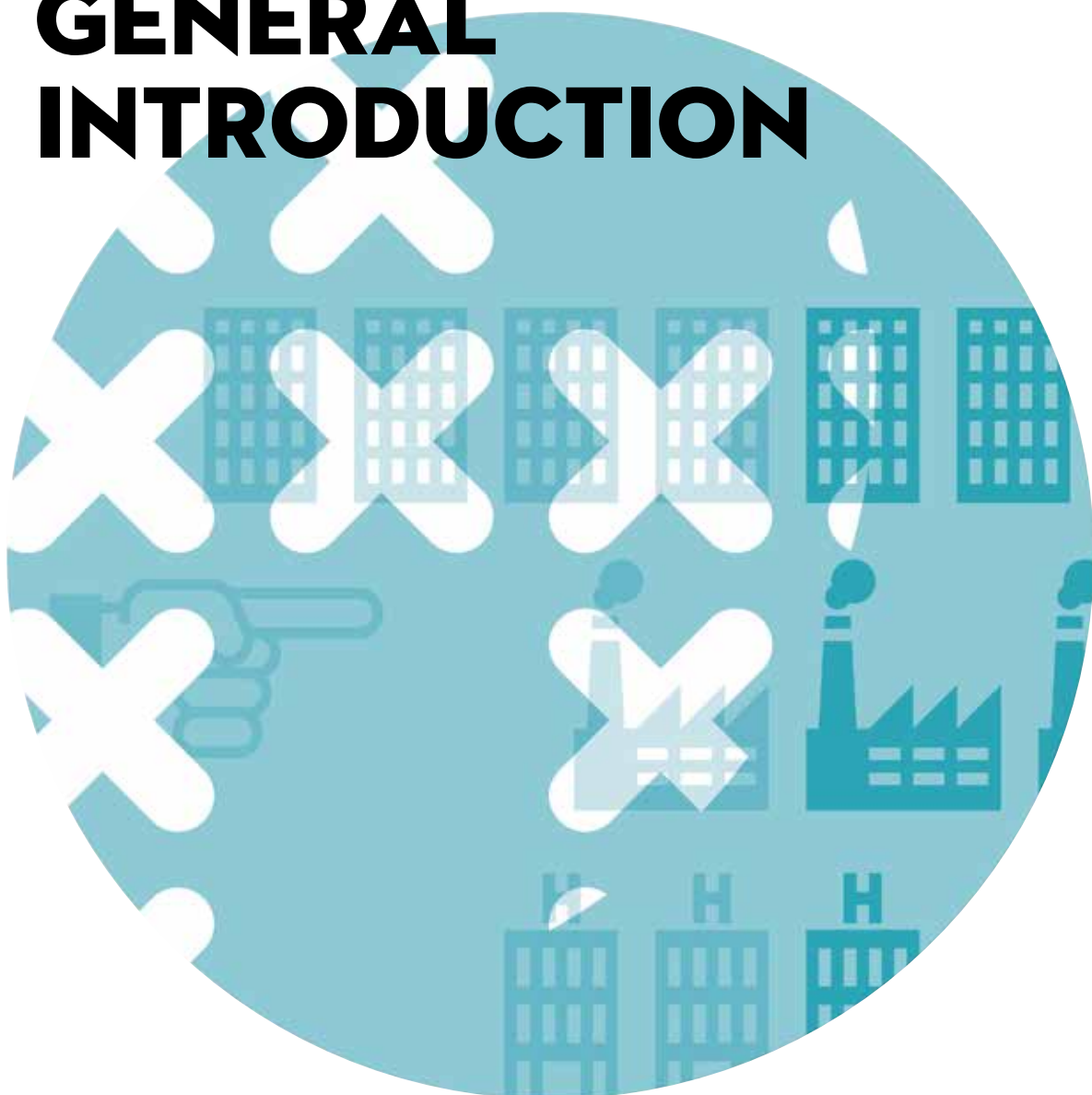
# LIVING WITH HIV

Implications for work participation

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## Chapter 1

# GENERAL INTRODUCTION



## HIV: A chronic disease

HIV became a chronic disease with the widespread availability of combination anti-retroviral treatment [C-art]. This has had an impact on both social and work participation, both of which are important factors in achieving a high level of well-being and life satisfaction.<sup>[1, 2]</sup>

In the Netherlands, the number of people with a chronic disease (including HIV) is expanding, as is the average life expectancy. In the future, increasing numbers of people will have to deal with a chronic disease. It is estimated that the number of individuals living with one or more chronic diseases will increase from 5.3 million in 2011 (32% of the general population) to 7 million by 2030 (40% of the general population).<sup>[3]</sup> This implies that the number of people with a chronic disease in the labour force will also increase. In 2012, 1 out of 5 people of the potential labour force suffered from a chronic disease.<sup>[4]</sup> In the past decades, the Dutch government introduced several changes in rules and legislations to increase work participation among individuals with a chronic disease.<sup>[5]</sup> Nonetheless, the level of work participation among people living with a chronic disease in the Netherlands is estimated at 25-57%, which is substantially lower than in the general population.<sup>[6]</sup> One of the problems is that healthcare professionals fail to sufficiently take into account the work situation of individuals with a chronic disease.<sup>[7]</sup>

## HIV

Since the introduction of C-art in 1996, the morbidity and mortality among people living with HIV (PLWH) has been decreasing.<sup>[8, 9]</sup> Nowadays, after their initial diagnosis, PLWH on therapy are now able to live relatively normal lives. However, it remains unclear what effect HIV has on individual life expectancy and future plans<sup>[10]</sup>. In those countries where medication is available, HIV can be considered a chronic disease. Nevertheless, the course of an HIV infection (even with medication) can be unpredictable, characterised by alternating periods of fluctuating quality of physical and mental health, affecting the person's quality of life.<sup>[11]</sup> PLWH need to learn how to deal with the challenges of living with a chronic disease.

In 2015 an estimated 36.7 million people worldwide were HIV infected (UNAIDS, 2016). In Europe, in 2015, the number of new HIV infections was 29,747, with an average rate of 6.3 per 100,000. The highest overall rate was in the age group 25-29 years (14.8 per 100,000). Therefore, HIV remains a major health concern, also in Europe with an increasing number of new infections (15% in 2015), especially among men who have sex with men (MSM).<sup>[12]</sup>

In the Netherlands, at the end of 2015, there were 22,900 PLWH. As of May 2016, 18,866 people were in clinical care, among which 3,591 women with a median age of 48 years and an average of duration of infection of 10.7 years. Of PLWH, the majority was aged 45-54 years (n=6,399). From the total group, 60% originated from the Netherlands, among MSM 71%, and among women and heterosexual men, 37%. In the Netherlands, the majority of new infections (64%) is among the group of MSM.<sup>[13]</sup>



## Impact of HIV on daily life

Although scientific literature on HIV and daily functioning is growing, there are few reports on the extent of limitations in daily living among PLWH. PLWH may face a wide variety of issues, related to their physical, psychological and social condition.<sup>[14]</sup>

There is some evidence regarding physical issues, such as fatigue. Fatigue has a high prevalence among PLWH, ranging from 33-88%, which has a considerable impact on their quality of life.<sup>[15, 16]</sup> A relationship between fatigue, and anxiety and depression, has also been reported.<sup>[16]</sup> Depression has also been described in relation to other issues, such as stigma, dilemma of disclosure, and side-effects of medication. PLWH are more often affected by depression compared to non-PLWH, probably related to these stressors<sup>[17]</sup>. Neurocognitive impairment is another problem affecting the daily living of PLWH. Although the use of antiretroviral therapies has diminished the incidence of HIV-associated dementia, minor cognitive problems remain a problem among PLWH.<sup>[18]</sup> PLWH with cognitive impairment are reported to perform worse on measures of everyday functioning.<sup>[19]</sup>

Stigma is one of the main issues which impacts on daily living of PLWH. HIV-related stigma refers to the process of labeling and the social isolation of PLWH.<sup>[20]</sup> In contrast to other chronic diseases, HIV (as an infectious and predominantly sexually transmitted disease) is not yet broadly socially accepted.<sup>[21]</sup> Studies conducted in various countries show that HIV-related stigma contribute to psychological distress and other physical and mental health outcomes.<sup>[22, 23]</sup> Strongly related to stigma is the dilemma of disclosure. Whether or not PLWH conceal their HIV status from partners, family, friends and colleagues generally depends on the way in which communities stigmatise PLWH, and how they perceive themselves. Many PLWH choose to disclose their status only to sexual partners, although the level of disclosure varies between countries. In non-Western countries the level of disclosure is lower than in Western countries.<sup>[24]</sup>

## Impact of HIV on work participation

Work participation implicates structuring of the day, social contacts, identity, having a goal in life, and financial resources.<sup>[9, 25, 26]</sup> Although the influence of HIV on employment appears to be high, actual evidence regarding HIV and employment is scarce. Some studies report that, among PLWH, the level of unemployment is high, ranging from 45-65%.<sup>[30-32]</sup> In the Netherlands, it is not exactly known what the level of work participation is among PLWH.

In 2008, the Cirion Foundation<sup>1</sup> and the Dutch HIV Association initiated the 'Expert group HIV and Work'. This multidisciplinary group consisted of various healthcare professionals involved in HIV care, including, for example, an occupational health physician, a HIV physician, a HIV nurse, a psychologist, and a social worker. The aim of this expert group was to create a multidisciplinary

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<sup>1</sup> Cirion Foundation, established in 2000, stimulates local and international cooperation in order to facilitate a multidisciplinary and integrated approach of solving issues related to infectious diseases.

platform in order to share knowledge and practical experiences about PLWH and work participation. The experience of the members of this group, and an inventory literature search, revealed that PLWH in the Netherlands faced many work-related issues and that the guidance provided was insufficient. To improve supportive care and guidance for PLWH and work-related concerns, a multidisciplinary guideline was developed.

## Outline of this thesis

The first step in the guideline development process was to identify employment-related concerns of PLWH in the Netherlands. The results of this qualitative study (**CHAPTER 2**) formed the basis for the key questions which were addressed in the multidisciplinary guideline ‘HIV and work’. For the guideline, a comprehensive literature search was conducted and, based on the literature and experiences from experts in this field, recommendations for practice were formulated. The process of guideline development is described in **CHAPTER 3**. One of the key questions for the guideline was how the vocational care for PLWH should be organised. A gap seemed to exist between the needs of PLWH and the support provided by the healthcare professionals involved.<sup>[28]</sup> In the vocational counselling of PLWH, several healthcare providers may be involved, such as the general practitioner, HIV nurse, HIV physician, occupational health physician, and psychologist. Because the HIV nurse has a central position in the care for PLWH in the Netherlands, and have a confidential relation with their patients and are easily accessible, it was recommended that the HIV nurse could also play a central role in the vocational counselling. However, at that time, it was unclear how often HIV nurses actually dealt with work-related issues and whether this role would fit in their competences. Therefore, we examined the current contribution of HIV nurses in vocational counselling and investigated their gaps and needs in this area (**CHAPTER 4**).

Various determinants of employment among PLWH have been identified and described in the guideline.<sup>[9, 25, 29, 33-35]</sup> For example, HIV-related stigma and discrimination, physical problems, changing health status over time, side-effects of medication, problems with managing the HIV infection at work, and gaps in work, were addressed. In the Netherlands, stigma and disclosure were the main negatively associated work-related issues for PLWH; however, a thorough insight into the available literature on work-related disclosure and stigma was lacking. Therefore, we conducted a scoping review of the literature to enlarge knowledge on this topic and identify ways to improve counselling (**CHAPTER 5**).

The development of the guideline acknowledged the relevance of further insight into vocational functioning among PLWH, but also highlighted that quantitative data on PLWH and work were limited, and not yet available for the Netherlands. Also, insight into employment status and associated determinants of different subgroups among PLWH, as described in the guideline, was lacking. In order to add to this knowledge gap, a cohort study (called the TREVI study) focusing on native Dutch

PLWH, was set up. One of the aims of that study was to investigate the level of work participation and the related determinants. **CHAPTER 6** presents the baseline measurements of that study.

Little is known about productivity losses (absenteeism and presenteeism) among PLWH. Various health conditions are associated with productivity loss at work, such as impaired mental health and musculoskeletal complaints.<sup>[36, 37]</sup> However, it remains unclear whether this also applies to PLWH and if the productivity losses among PLWH are different compared to the general population. In the TREVI study we also addressed productivity losses among the working PLWH; these data were compared with the general Dutch population. **CHAPTER 7** presents the results of that study.

As mentioned, data on HIV and work, as well as other aspects of daily functioning, are still scarce and are not yet available for all countries. Comparison of vocational functioning between different countries can be important to identify societal differences in each country and to address specific needs for counselling. Therefore, another cohort study with the same aims as the TREVI study was set up in Barbados. **CHAPTER 8** presents the results of a study in which a comparison was made between the Netherlands and Barbados, i.e. two high-income countries, but with a different social and cultural setting.

**CHAPTER 9** presents a general discussion of all these studies.

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# LIVING WITH HIV

Implications for work participation

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## Chapter 2

### **EMPLOYMENT- RELATED CONCERNS OF HIV-POSITIVE PEOPLE IN THE NETHERLANDS:**

Input for a multi-  
disciplinary guideline

**Authors** Wagener MN, van Opstal SEM, Miedema HS, Brandjes DPM, Dahmen R, van Gorp ECM, Roelofs PDDM.  
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### Abstract

**PURPOSE** Finding and keeping employment is difficult for people with HIV. To improve supportive care for people with HIV and employment-related problems, a multidisciplinary guideline was developed in the Netherlands in 2010/2011. To identify the employment-related concerns of people with HIV and to formulate the key questions for the guideline, we conducted a qualitative study. The results of this study are described in this article.

**METHODS** This study was performed in three HIV-treatment centers in the Netherlands. In total 18 participants participated in three focus-group interviews and nine participants were interviewed individually. The data were transcribed ad verbatim and were analyzed according to the principle of constant comparison.

**RESULTS** Our findings indicate that people with HIV in the Netherlands face many work-related concerns. The themes which emerged from this study were disclosure, stigma and discrimination, knowledge about HIV, physical and psychological factors, working conditions, absenteeism, reintegration, and dismissal and counselling.

**CONCLUSIONS** This study provides insight about employment-related concerns for people with HIV living in a Western country. It formed the basis for the key questions which were addressed in a multidisciplinary, evidence-based guideline “HIV and work”. Finally, it gives leads for further scientific research and opportunities for improving the vocational guidance of people with HIV.

### Key Words

*HIV*

*Employment*

*Qualitative  
research*

*Vocational  
guidance*



## Introduction

With the introduction of highly active antiretroviral therapies (HAART) in 1996, HIV has become a chronic disease.<sup>[1,2]</sup> This change made it possible for people with HIV to return to work again. However, for people with HIV, maintaining their employment and returning to work is challenging.<sup>[2-6]</sup>

Studies in Western countries have shown that the unemployment-rate among HIV-infected people ranges from 45-60%. The impact of HIV on work participation also seems large, causing high macro-economic costs due to sick-leave, disability benefits, and loss of knowledge and skills.<sup>[6-8]</sup>

Stigma and discrimination seem to be the main employment-related problems for people with HIV.<sup>[9,19]</sup> Stigma is a possible barrier for reintegration, and because of the HIV-related stigma people with HIV are afraid of disclosing their HIV-status at the workplace<sup>[11]</sup>. Fear for discrimination appears to be a serious problem for people with HIV also.<sup>[12,13]</sup>

Physical and psychological issues, like fatigue and cognitive impairment are also a problem for optimal functioning at work as shown in previous studies.<sup>[14,15]</sup> There is a clear relation between neuro-cognitive functioning and stability and success in work.<sup>[16]</sup>

Previous research showed that the patient's skills, work history, social services and the working environment are important issues as well.<sup>[2, 3, 6, 15, 17, 18]</sup>

Although previous research on HIV and work has been done, only a few studies in Western European countries are conducted. Until recently, there was no scientific research available about the Dutch situation, and also in daily practice there was hardly explicit attention for work-related issues. For example, the level of work participation was not registered, and no specific counseling was provided for people with HIV and problems as it pertains to work. However, in daily practice it is signaled that people with HIV in the Netherlands do face work-related problems. These problems are often not recognized and registered by most of the health-care providers, employers, and the society. Many health-care providers may be involved in the guidance of people with HIV with employment-related concerns, such as the general practitioner, HIV-treating physician, HIV-nurse, social worker, and occupational health physician.

To improve supportive care for people with HIV and employment-related problems in the Netherlands, a multidisciplinary, evidence based guideline "HIV and work" was developed in 2010/2011. Identifying the employment-related concerns of people with HIV was the first step in developing this guideline. These themes provided the basis for the key questions of the guideline.

Therefore, we conducted a qualitative study, with the following research question: "What are the employment-related concerns of people with HIV in the Netherlands?"

## Methods

### **Study context and design**

This qualitative study was conducted in the three main HIV-treatment centers of the Netherlands, Amsterdam, Rotterdam, and Leiden. Two authors (MW and PR) were involved in the development of

the guideline “HIV and work” (see Appendix) and conducted the main part of this study. They were external researchers, not involved in patient-care, and so did not have any relation with the participants. Both researchers had experience with qualitative research and followed additional training on HIV. Because the main goal of our research was to explore the experiences of people with HIV as it pertains to work, a grounded theory approach was used.<sup>[19]</sup> According to the Dutch Medical Research Involving Human Subjects Act (WMO), this study was exempted from a medical ethical review. The study complied with The Netherlands Code of Conduct for Scientific Practice from the Association of Universities in the Netherlands (VSNU).

### **Data collection**

In order to identify the perspectives of people with HIV both focus-group interviews and individual interviews were conducted.

The focus-group interviews were led by a trained moderator (PR) and lasted about 60-90 minutes. One of the researchers (MW) also joined the focus-group interviews to make notes and to assist the moderator. A question-protocol, based on current insights from scientific literature about working with HIV, was developed to structure the conversation. This protocol started with a general question about people’s experiences with employment if it pertains to HIV and was followed by questions about themes which emerged from literature. These themes were motivation to work, physical and psychological symptoms, medication, positive and negative experiences in working life, role of the manager, experiences with counseling, and suggestions about improving counseling. Although questions about these themes were used to start the conversation, participants were encouraged to discuss all their experiences and opinions freely.

After carrying-out the focus-group interviews, individual interviews with HIV-patients were conducted in order to complement the data derived from the focus-group interviews. These interviews were conducted at a place chosen by the participant, such as the hospital, at home or in a public building. The interviews lasted approximately 60 minutes and were conducted by trained students from the Rotterdam University of Applied Sciences under supervision of the researchers (MW and PR). A topic list was developed to structure the interview, comparable to the question-protocol that was used in the focus-groups. The focus-groups and individual interviews were audiotape-recorded with the participant’s written consent. After each interview the main findings were summarized to check their eligibility.

### **Participant selection**

We used a purposive sampling strategy aimed at composing heterogenic groups in terms of gender, age, origin and work status. People were eligible if diagnosed with HIV/AIDS, 18 years or older and under care of one of the three HIV-treatment centers. People were excluded if they were not able to speak Dutch. Patients were approached face-to-face by the HIV-nurse and if they were willing to participate, the researcher contacted them by telephone and email to explain all the details about the study. For each focus-group interview 12 patients were approached. For the individual interviews as many participants as necessary were approached until data saturation was reached.

**Data analysis**

The data were transcribed ad verbatim and were analyzed according to the principle of constant comparison.<sup>[20]</sup> The qualitative software program Atlas-ti (Atlas-ti 4, Scientific Software Development GmbH) was used. First two researchers (MW and SvO) individually read all transcripts and labeled key themes (interconnected/ overarching ideas). These general themes were discussed and subsequently coded all transcripts to generate subcategories for a broader understanding of the major themes. Disagreements were resolved by the third author (PR). The themes were also discussed by the Dutch HIV association and experts on HIV and work. Subsequently, all codes were structured, compared with the literature and categorized. In the final step the findings were summarized and suitable quotations were selected for illustration.

Results

Data were collected between January and April 2010. Some characteristics of the participants are listed in table 1. In total 18 participants participated in the three focus-group interviews (50%). In total nine individual interviews were conducted. Reasons for non-response were illness and fear for participation.

**Table 1 Characteristics of participants (n=27)**

	<i>Focusgroup (n=18)</i>	<i>Individual interview (n=9)</i>
Gender		
Female	7	1
Male	11	8
Dutch origin	15	8
Age (mean)	45	47
Work status		
Employed	15	7
Years since HIV-diagnosis		
0-5 years	4	4
5-9 years	5	3
≥10 years	9	2

The following themes emerged:

**Motivation to work**

Participants described a working life as the way to support for themselves and make their own living. One respondent said “You have to work, even if you are ill, you have to earn your own money”. Participants talked about the financial benefits of working and not being dependent of social services.

It also brings structure in their everyday life. “Without working, the day becomes a night and vice versa”. Participants talked about the social contacts with their colleagues and the desire of being a part of the society and making a contribution to the community. “Work is important to feel that you are a valuable member of the society”. Others talked about the satisfaction they get from their job and the feeling of participating in life.

### ***Disclosure***

After being diagnosed, participants had to choose whether or not to disclose their HIV status at work. Some participants described their HIV-status as a private matter and see no reason to disclose. “It’s nobody’s business”. “I don’t disclose my HIV-status at work, because it is irrelevant. I think it has nothing to do with my job”.

Some participants didn’t know if they were obligated to tell their employer about their HIV status. “I think you are not obligated to disclose your HIV-status, but it depends mostly on the kind of job you do”.

Fear for stigma and discrimination was the main reason not to disclose. “I think they wouldn’t have hired me if I told them I was HIV-infected at the application”. When participants decided to disclose, reactions were mixed. Some participants experienced positive consequences of disclosure. They felt relieved because they didn’t have to lie anymore about their health or hide their medicines. For some it even strengthened the relationships with colleagues. They felt more understanding in the case of illness and mental support of colleagues when they were feeling down. One participant described: “I also gained respect because they can see they don’t have to pity me and that I’m able to work normally”. Most participants who decided to disclose at their workplace, were only open to some people, either people they trusted or people who needed to know about their status. Most participants were open to their occupational health physician, because of his professional confidentiality. Some participants, especially those working as employer, didn’t want to tell the occupational health physician because they doubt his confidentiality.

### ***Stigma and discrimination***

All participants agreed that there is still a lot of stigma and discrimination about HIV. Participants discussed possible reasons for this stigma. One reason that came up, was the issue of guilt and responsibility. “People say that if you get infected with HIV nowadays, you have to blame yourself, because you should have had safe sex”. HIV is still linked to promiscuous behavior, homosexuality and drugs. “You could tell from the look on their faces that they were guessing how many guys I had slept with to get this”.

Some participants were so afraid of discrimination at work that they made up another disease to cover up symptoms or hospital visits. “There are so many similar diseases, which are more socially accepted, so I told them I had Pfeiffer”. “At my workplace, they know that I am taking medicines, but they think I have hepatitis. That is an easy way to cover up for the intake of my medicines”. For some participants who disclosed their status at work, the fear of stigma became reality. “There was a lot of gossip of colleagues”. “After disclosure she [a colleague] was checking me the whole time if I wasn’t

making any mistakes”. One participant decided to resign after experiencing negative reactions of colleagues. “I was able to handle all the gossip, but in the end I decided to choose for myself and go another way”.

It was clear for the participants that there is still a lot of ignorance about HIV, especially about the ways of transmission and the consequences of HIV. “They were worried about cups and door handles”. Participants discussed that a lot of people still have prejudices of HIV/aids from the eighties or nineties. “People still have that picture, they link HIV with aids, with dead, with danger”.

Participants discussed that the only way to reduce stigma is to disclose their HIV status and prove prejudices are unfounded. “If nobody tells, nothing will change and they would never see that we are pretty normal”.

### ***Knowledge about HIV***

One of the participants described that there is still a lack of knowledge about HIV at work. “They don’t know anything about it although they should inform themselves”. Another participant mentioned that in his company HIV is a quite common topic because many employees are gay and some of them are HIV-infected. One of the participants mentioned that information meetings at work can be very useful to share knowledge about HIV, reduce fear and to make policy.

Knowledge about laws and regulations is limited for some of the participants. For most of them it is still unclear if you are obliged to mention in a job interview that you are HIV-infected. “Can you be refused for a job if a health examination reveals your HIV-infection? I don’t know”. Other participants described that privacy-legislation is still unclear.

Media may play an important role in improving this situation. “The Netherlands are much too soft in all kinds of campaigns. Much too soft. People still think I can’t give a hand of sit on their toilet. That’s because of unawareness”.

### ***Physical issues***

Some participants mentioned that they have some physical complaints, such as fatigue or less energy, bothered them at work. Especially the time without medication was mentioned as a period with many physical complaints. “During the time without medication I was extremely tired”. Some of them think it is because of their age and/ or because they take medication for a long time. For most of the participants it is hard to say if their complaints are HIV-related. “I am regularly tired, and then I think it can be caused by my HIV or my irregular working hours”. One of the participants thinks that fatigue is the result of the stress after being diagnosed as HIV-positive. Others don’t have any problems with their energy-level. They work full-time without any problems. “I take one pill per day and that’s all”.

Most of the participants reported many side-effects of medication, such as lypodystrofia, weight loss, diarrhoea, tingling in legs and arms, dizziness, headache, sickness, nightmares, sweat, insomnia and concentration problems. In almost all cases the side-effects were worst in the beginning of taking medication. But changing medical regimes gave much improvement. “Since I have changed regime I sleep much better, but I still have concentration problems”.

Some participants discussed their resistance is reduced and recovery after sickness lasts longer than before. One of the participants said that she lives more conscious with more moments of rest to prevent HIV-related complaints and absenteeism. Another participant mentioned: “I am more conscious of the fact that life is ending, I am less careless”.

***Psychological issues***

After diagnosis most of the participants had psychological problems because they had to recalibrate their lives. “Your world collapses, after the diagnosis I went to the psychologist and met the HIV-nurse every week”. “It took me a couple of years to adapt and to realize I could still have a relationship. And now I have a normal life like everybody”. Some of the participants consulted a psychologist, mainly right after hearing the diagnoses. “I tried to handle it myself but the diagnosis had so much impact that I needed support”. Some of the participants joined a support group. One of the female participants joined a women support group which was very helpful for her. “Because there are not so many women with HIV, it felt good to meet each other and talk about all kind of things”.

One of the issues which is strongly related to psychological well-being is disclosure. Whenever people experienced negative reactions at work on their HIV-infection, they felt stressed or unsafe.

Some participants who didn’t disclose their HIV status described their fear for disclosure, which resulted in stress and the need to lie to their colleagues. Other psychological problems that were mentioned were depression and anxiety. It is not clear for the participants if these problems are side-effects of medication.

Some participants mentioned the stress they experience of taking medication. “If I travel [for business] from one country to another or if I move from one hotel to another, it can be pretty stressful if I can take my medication on time”.

***Working conditions***

It is important for participants to be able to adjust their work demands to their physical and psychological abilities if necessary. One of the participants, who works as a steward, was able to change his flight schedule. “You have to take your medicines at 8 in the morning and 8 in the evening, so you can imagine it is quite difficult within the different time zones”. So I asked my employer if I could only fly in Europe”. It makes it easier for participants if they can arrange their own time schedule. Flexibility is also appraised by participants, when it comes to hospital visits. “I was able to reschedule my day off at Tuesdays, because that was the day the internist was available for my hospital visits”.

Another factor of influence is how physical demanding a job is. “I had all kind of jobs, like cleaning and working in a factory. The job at the factory was physically too heavy for me”. A nurse told the following about her job: “I have irregular shifts, also night shifts. But because of the medication and fatigue, I cannot do the night shifts anymore, because I’m not attentive enough”.

The attitude of the manager is an important factor for the participants. His or her (expected) attitude towards HIV is of significant influence on the decision to disclose or not. It is also important if the manager is willing to make adaptations when needed, for example in working hours. “I can always take a few hours off when the results of an examination in the hospital are disappointing”.

***Absenteeism, reintegration and dismissal***

The work status of the participants differed a lot. Some of them worked fulltime without problems, while others couldn't work anymore because of the symptoms of HIV.

Most of the participants were absent for a longer period before diagnosis because of physical symptoms. After diagnoses most participants were absent because of mental problems with the diagnosis and problems with medication.

As earlier mentioned some of the participants experienced more physical problems than before their HIV-infection. They have the feeling that their resistance is lower so they are more susceptible to infections. In their perception this causes more absenteeism, mostly short and frequent absence: "I had a conversation with my employer last week because of my frequent absenteeism". Almost all of the working participants mentioned that their employers pay a lot of attention at preventing frequent absenteeism. One of the participants said: "If I call my employer to tell him that I am ill, he says that I have to come to my work to show him how ill I am, so I have to go to my work by bike and then he doesn't allow my illness. It is really difficult for me".

One participant got fired shortly after disclosure: "I was dumped. They just didn't want me to work there anymore because of my HIV status. It is very harsh, because I was able to do my job".

Some participants didn't have a job at the moment of the interview. One of them said that it is hard to find a new job but HIV is not the main reason for that: "I find that irrelevant, I don't tell a potential employer about my HIV-infection, I think that a chronic disease doesn't have to do anything with work".

***Counseling***

Most of the participants were satisfied with the given support. Especially the HIV-nurse and occupational health physician were mentioned to be supportive. The opinions of the participants differed about the role of the occupational health physician. This seemed to be related to the disclosure of the HIV-status to the occupational health physician. When the occupational health physician knew about the HIV-status most of the working participants were happy with his support. "For me it was very important that I could trust the occupational health physician, he was very helpful in my conflict with my employer because he was unprejudiced".

Another possible advantage of the role of the occupational health physician is the advice to the employer about employability without mentioning HIV, as well as making up a plan for reintegration. Some of the participants experienced that their occupational health physician didn't know anything about HIV and therefore the support wasn't helpful. Other have never met a occupational health physician because they were never absent from work.

All the participants were very positive about the support of the HIV-nurses because they know a lot and give a lot of information. "You have a doctor for the medical support and the HIV-nurse for the rest, for example if I should tell about my HIV-infection at work". Furthermore an advantage of the HIV-nurse is that they are very accessible, in contrast to a physician. "Even when I called her from work and said that I felled bad, I could come during her break".

The general practitioner was consulted by some of the participants with work-related problems. "When I started medication I had so many complaints that I couldn't work anymore. The general

practitioner sent me to a psychologist because it was mainly caused by stress”. Some of the participants describe the lack of knowledge of the general practitioner. Although I told him I might have HIV, he sent me back home with medication for a candida infection”. Another participant described that his general practitioner didn’t even know about combination therapy and therefore thought that he would die soon.

## Discussion

This study explored the work-related concerns of people with HIV in the Netherlands. It shows that they face different issues in maintaining their career. Most of the participants of this study had a paid job but had to deal with all kinds of problems. The themes which emerged from this study were disclosure, stigma and discrimination, knowledge about HIV, physical and psychological factors, working conditions, absenteeism, reintegration, and dismissal and counselling. These themes were discussed in a multidisciplinary group of experts which was responsible for the development of the guideline. In this group of experts all relevant professional associations and patient association were involved. Based on the themes five key question for the guideline were formulated, comprising all nine themes. An example of a key question is: “What is the role of disclosure about HIV in relation to employment?”

Participants described that having a paid job is important because it structures their lives, brings social contacts and financial independence, which is consistent with prior research.<sup>[2, 6, 17]</sup> The main issue people with HIV have to deal with is disclosure at work. Most participants did not disclose their HIV-status at work because they thought that it had nothing to do with their work. Another reason for the participants not to disclose their HIV-status at work was fear of stigma and discrimination. On the other hand for some participants it was unclear if they were obliged to tell about their HIV-status. They also doubt the professional confidentiality of the occupational health physician.

All participants mentioned that there is still a lot of discrimination, prejudices and ignorance about HIV. Participants were afraid of losing their job or not getting a job at all when they would disclose at an interview. On the other hand they acknowledged that if everybody keeps quiet nothing will change and HIV will remain a very sensitive disease. These findings about disclosure, stigma and discrimination, taken together with other studies<sup>[21-23]</sup> suggest that it remains important to stimulate education about HIV. Further research to the best way to reduce stigma is recommended.

Another important result of this study is that many participants experienced physical and psychological problems which influenced their work. Especially just before and after diagnosis participants experienced physical symptoms as fatigue, concentration problems and all kinds of side-effects of medication. The period after diagnosis was for most of the participants also very stressful, because they had to recalibrate their lives including work. These results confirm the conclusions of earlier studies which concluded that fluctuations in the course of the disease, side-effects of medication, and physical and psychological complaints seem to be negatively associated with employment.<sup>[3, 5, 6, 11, 14, 15, 17, 18, 24, 25]</sup> These results confirm the importance of good counselling focused on work of people with



HIV. The advice is to take into account the different stages in the disease process and to map possible factors which may cause problems at work.

Participants with a paid job described that working conditions are important for their well-being at work. For example, hospital visits may cause stress if they have to be planned during work-time and people who work around the world may have troubles with taking medication. Participants mentioned that it is very helpful if working conditions are adaptive. In counselling of people who will return to work, it is important to pay attention to working conditions and to map if the job matches the capability/ capacity of the employee. Since the home situation and psychological state may influence employment it is important to map the psycho-social situation. The general practitioner should do this, but health care providers, such as the social worker, involved in a later stage should inform.<sup>[1, 26]</sup>

Earlier research at determinants of work of people with HIV was mostly conducted in the US or Canada. Fear of loss of social services was one of the main factors related to employment.<sup>[2, 3, 11-13, 15, 17, 18, 25, 27]</sup> In the Netherlands the insurance system is different than in these countries. Fear of loss of social services is not necessary\*. Nevertheless some participants thought they might lose their right on social services because of their HIV-infection. Therefore knowledge about laws and regulations should be spread among health care professionals, employers and people with HIV.

It has to be noted that this was a qualitative, explorative study which revealed the main themes for people with HIV in the Netherlands. The participants varied in gender, origin and work status and are representative for people with HIV in a Western country. Saturation of emerging employment-related themes was reached, and the themes were affirmed by experts and the patient association. However, these themes should be further investigated in prospective quantitative research to determine the prevalence of the different themes and to gain insight in the relation between for example work, physical complaints and the stage of the disease. Furthermore, research to possible interventions, such as an intervention to reduce stigma, and to stimulate return to work is recommended.

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\* **Relevant Dutch Social Security Laws and insurance:**

**Equal Treatment Act:** This law states that unfair treatment on the grounds of a handicap or chronic illness, including HIV, in the work environment or at a private practise is prohibited.

**Medical Examinations Act:** The employee is under no obligation to reveal his or her HIV-status during the course of a job interview. The employee retains the right of privacy.

**The Eligibility for Permanent Incapacity Benefit (Restrictions) Act:** The objective of this law is to improve the chances of reintegration and/or the return to the labour market, by giving the employer and employee more responsibility for this process. In case of illness the employer is required by law to continue paying wages for 2 years.

**Capacity for Work Act (WIA):** After two years of illness the employee can apply for a WIA allowance. This amount to 75% of the employee's most recent salary

**Dutch Unemployment Benefit:** In case of unemployment people can apply for a Dutch unemployment benefit.

**Health Care Insurance:** All citizens are obliged to take out Dutch Health Care insurance.

## Conclusion

This qualitative study provided a thorough insight into a set of employment-related concerns from the perspective of people with HIV in the Netherlands. This study makes clear that further scientific research is recommended, especially quantitative, prospective research, and intervention research. The insights, gained in this study, provided the basis for the development of the multidisciplinary, evidence-based guideline for HIV and work. This full guideline and a summary for daily practice were published in 2012 and are digitally available in Dutch.<sup>[28]</sup> An English summary for daily practice will be digitally published in 2014. In practice it is important that knowledge about HIV and laws and regulations will increase, so stigma and discrimination could be reduced. Furthermore it is important for different professionals to pay attention at the process of disclosure, the psycho-social situation and working conditions.

## Appendix: Information about the guideline “HIV and work”

The multidisciplinary, evidence-based guideline was developed by a multidisciplinary core group in which all involved professional associations were represented. The guideline was developed according to “evidence-based guideline development (EBRO)” methods (CBO, 2004). The guideline is authorized by all involved professional associations and the Dutch HIV Association. The guideline and a summary for daily practice are available in Dutch. An English summary for daily practice will be digitally published in 2014.

### Organization and development:

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T. (010) 794 54 54, [www.kenniscentrumzorginnovatie.nl](http://www.kenniscentrumzorginnovatie.nl)

### The guideline is available on:

- <http://zorginnovatie.hr.nl/nl/Projecten/Zelfmanagement-en-Participatie/HIV--Arbeid/>
- the websites of the professional associations
- the website of the Dutch HIV Association ([www.hivnet.org](http://www.hivnet.org))
- [www.positiefwerkt.nl](http://www.positiefwerkt.nl)
- [www.kiza.nl](http://www.kiza.nl)

### The guideline has been authorized by:

- Dutch HIV Association (HVN)
- Dutch Association of HIV-treating physicians (NVHB)
- The Netherlands Society of Occupational Medicine (NVAB)
- Professional Association of HIV/AIDS Nurses) collectively affiliated with Dutch Nurses' Association (V&VN VCHA)

- Occupational Social Workers Professional Association), part of the Dutch Association of Social Workers (NVMW)
- Dutch Association of Insurance Physicians (NVVG)
- Association of Occupational Health Nurses (BAV)
- Dutch Institute of Psychologists (NIP)
- Dutch Association of Labor Experts (NVvA)

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- Occupational Therapy Netherlands

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# LIVING WITH HIV

Implications for work participation

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## Chapter 3

# THE DEVELOPMENT OF A MULTIDISCIPLI- NARY, EVIDENCE- BASED GUIDELINE FOR “HIV AND EMPLOYMENT”



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### Abstract

The objective of this study was to develop a multidisciplinary guideline that supports the care and vocational rehabilitation of HIV-infected people with employment-related problems.

The guideline was developed according to the “evidence-based guideline development” method developed by the Dutch Institute for Health Care Improvement. This method consists of the following steps: forming a multidisciplinary core group and an expert panel, formulating key questions, searching and appraising the available literature, formulating considerations and recommendations, peer review of the draft guideline, and the authorization of the final guideline.

All relevant professional associations were represented in the core group that was assembled to develop the guideline, i.e. HIV doctors, HIV nurses, general practitioners, occupational health physicians, psychologists, social workers, occupational health nurses, vocational experts, and insurance physicians. Five key questions for the guideline were formulated with the following themes: determinants of employment, disclosure and stigma, self-management, interventions, and the organization of care. In the literature review on these topics, 45 studies met the inclusion criteria. The methodological quality of the included articles was poor. Factors, such as patient preferences and medical/ethical issues were considered. The recommendations in the guideline are a weighting of the scientific evidence and the considerations of the core group.

The guideline, and its summary for daily practice, clarifies the most important barriers and facilitators to people with HIV either staying at work or returning to work, and it constitutes a clinical, easy-to-use guideline for health care providers and how they can support people with HIV who want to work.

### Key Words

*HIV*

*Employment*

*Guideline  
as a topic*

*Vocational  
rehabilitation*

*Organization  
of care*

## Introduction

Since the introduction of highly active antiretroviral therapies (HAARTs) in 1996, the incidence and mortality of HIV-infected people has decreased and HIV has become a chronic disease.<sup>[1, 2]</sup> This change in life expectancy has shifted the focus from the physical condition to activities in daily life.<sup>[3]</sup> However, individual life expectation and future planning among people with HIV remain uncertain<sup>[4]</sup>, and are characterized by periods of fluctuating health.<sup>[5]</sup> The prevalence of HIV-related and non-HIV-related diseases and symptoms seem to be increasing.<sup>[6, 7]</sup> HIV-infected people may have physical, neurological and psychological impairments, which impacts upon both their quality of life and daily life, including work.<sup>[8]</sup>

For people with HIV, taking their place in society and having a job helps them to structure their life and forge social contacts, provides identity and helps to set targets and obtain resources.<sup>[2, 9, 10]</sup> However, people with a chronic disease still face problems in keeping their job, or returning to work. Dutch research shows that changes in policy, aimed at facilitating employment and increasing employability, have not resulted in an increase in the employment of people with a chronic disease.<sup>[11-13]</sup> Studies in Western countries have shown that the unemployment rate among HIV-infected people ranges from 45 to 60%, compared to an unemployment rate among the general population in the Netherlands of 5.3%. A HIV infection can either lead to the resignation of the patient or creates barriers to returning to work.<sup>[2, 10, 14-16]</sup> This impact of HIV on employment causes high macro-economic costs due to sick leave, disability benefits, and the loss of knowledge and skills.<sup>[10, 17, 18]</sup> HIV patients with a low socioeconomic status, women, and poorly educated people are particularly vulnerable to losing their job.<sup>[19]</sup>

Although research emphasizes the importance of supporting people with HIV with employment-related concerns, there is insufficient understanding of effective interventions.<sup>[18]</sup> A big gap exists between the needs of people with HIV and the current support given by professionals.

Given this relevance, it is surprising that there is no relevant policy or guideline.

Therefore, the objective of this project was to develop a guideline that supports the care and vocational rehabilitation of HIV-infected people with employment-related problems. This guideline integrates evidence-based insights about HIV and employment together with expert opinions and provides recommendations for HIV-infected people and their healthcare providers.

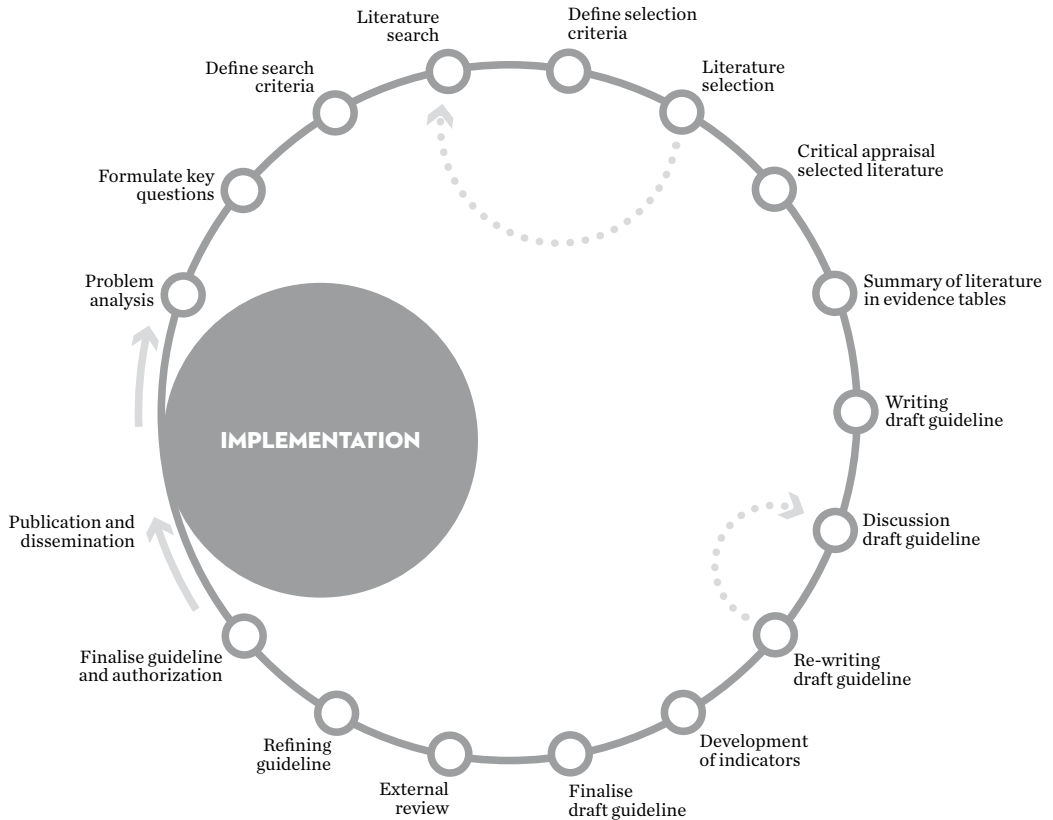
The development process of the guideline and its main content are described in this article.

## Methods

### **The guideline-development process; a step-by-step procedure**

The guideline was developed according to “evidence-based guideline development (EBRO)” method developed by the Dutch Institute for Healthcare Improvement CBO (fig. 1).<sup>[20]</sup> The EBRO-method is considered “state of the art” in Dutch health care. This method consists of different steps explained in the following paragraphs.

**Figure 1 Guideline development cycle<sup>[20]</sup>**



### Multidisciplinary core group and expert panel

The guideline-development process started in January 2010 by forming the multidisciplinary core group. In this core group all professional associations that were involved were represented, such as HIV physicians, HIV nurses, family doctors, occupational health physicians, psychologists, social workers, occupational health nurses, vocational experts, and insurance physicians. In addition to the core group, an expert panel was formed. A second representative of the professional associations and other experts on HIV and employment participated in this group. The Dutch HIV Association (patient association) was represented in both groups. The core group met five times: in April 2010, June 2010, January 2011, April 2011 and June 2011. They also had intermediate contact by e-mail or telephone about draft versions of the guideline. The expert group was only involved in postal rounds but it reviewed every step in the guideline-development process.



### **Formulating main themes and key questions**

Three focus group interviews and individual interviews were conducted in order to identify the perspectives of HIV patients about employment-related issues (Wagener et al, 2014). These interviews were organized in three HIV-treatment centers in the Netherlands. The sampling strategy aimed at composing heterogenic groups in terms of gender, age, origin and work status. In order to identify the perspectives of the healthcare professionals, semi-structured questionnaires were also distributed. The focus-group interviews were attended by 14 patients with HIV, while 9 patients with HIV were interviewed individually. All interviews were tape recorded, with the consent of all participants, and the interviews were transcribed ad verbatim. The semi-structured questionnaire was filled in by 18 healthcare professionals. The data were analyzed according to the principle of constant comparison (Boeije, 2010). First two researchers individually read all transcripts and labeled key themes. They then discussed these general themes and subsequently coded all transcripts to generate subcategories for a broader understanding of the major themes.

Based on the results of these interviews, the core group decided upon the main themes of the guideline, and formulated five key questions.

### **Literature search**

To generate an overview of the scientific literature on the key questions, we systematically searched the following databases: Medline, Embase, Cochrane Library, CINAHL, and PsychINFO. Relevant articles were identified using a sensitive search strategy recommended by the Cochrane Collaboration.<sup>[21]</sup>

To capture the highest number of relevant articles, varieties of the keywords “HIV” and “Employment” were combined in the electronic-sensitive search (Appendix 1). The searches were performed in September 2010 and were limited to articles published after 1995 because of the introduction of HAART in 1996. Two independent reviewers (M.W. and P.R.) selected relevant articles based upon the list of titles and abstracts. Studies were considered eligible if they were presented in an original article, examined HIV-infected individuals over 18 years of age, had employment as an outcome measure and had been conducted in a Western setting. There were no restrictions on the publication language. We excluded case reports, letters, newspaper articles, books and dissertations. To confirm their eligibility, the selected articles were read in full. Any dissensus was resolved through discussion, or through recourse to an independent author (H.M).

### **Methodological quality assessment of individual studies**

The methodological quality of the eligible articles was assessed independently by two reviewers (M.W. and P.R.), using appropriate assessment forms for the different study designs from the Dutch Cochrane Centre (<http://dcc.cochrane.org/dutch-cochrane-centre>).

Subsequently, the scientific evidence on a specific topic was summarized and the quality score of the described studies resulted in four different levels of evidence (Table 1).

**Table 1 Levels of evidence**

<i>Level of evidence</i>	<i>Conclusion based on...</i>
1	Systematic review/meta-analysis or at least two independently, properly conducted studies, such as a randomized, double blind trial or a prospective cohort study.
2	One study, such as a randomized, double blind trial or a prospective cohort study, or at least two independently conducted studies, such as a clinical trial or a prospective cohort study without all the features mentioned above.
3	A non-comparative study, or one of the studies mentioned in level 2.
4	Expert opinion

**Considerations and recommendations**

Beside the scientific evidence, other aspects can also be important for a recommendation related to a key question. These aspects, called “considerations”, comprise patient preferences, the availability of facilities, medical/ethical issues, or organizational aspects.

In the considerations, the evidence-based conclusion is placed in the context of daily practice. In the absence of scientific evidence or in case of contradictory results, the expert opinion is more predominant and can also result in a consideration.

These considerations were formulated by the core group and reviewed by the expert group. They are described concisely so they are clear for both patients with HIV and their care-providers.

**The draft and validation of the final guideline**

The draft guideline was written by the core group and reviewed by the expert group. Subsequently, all the professional associations were asked to review the draft guideline and place it on their website for commentaries of their rank and file. Taking into account all commentaries, a final version of the guideline was written and sent for approval to all the participating organizations.

Results

**Key questions**

- The themes discussed in the multidisciplinary panel led to the formulation of the following five key questions:
- 1 Which determinants play a role in the employment of people with HIV?
  - 2 What is the role of disclosure about HIV in relation to employment?
  - 3 To what extent does self-management play a role in relation to the employment of people with HIV?
  - 4 Which interventions are effective in stimulating the work participation of people with HIV?
  - 5 How should the care around employment-related problems for people with HIV be organized?

**The selection of studies for the guideline**

A total of 4344 citations were retrieved from electronic search (EMBASE, Medline, Cochrane Li-

brary, CINAHL, PsychINFO). Figure 2 shows the flow of studies through the selection process. Many abstracts and articles were excluded because employment was not an outcome measure. Finally, a total of 45 studies met the inclusion criteria. The methodological quality of the articles included was poor. Most articles described poorly conducted and/or reported small cross-sectional studies, qualitative studies and narrative reviews. This implied that the level of evidence of the conclusions was 3 or 4 (table 1).

**Figure 2** *Selection of the studies*



**Considerations and recommendations**

Once the evidence had been compiled, the considerations and recommendations were formulated.

**Guideline contents and summary for daily practice**

The guideline includes a general introduction about HIV and employment. Subsequently all key questions are described with the scientific evidence, considerations and recommendations. The outline of the guideline is shown in table 2. Furthermore we developed a summary for daily practice, which is also available in English (<http://zorginnovatie.hr.nl/PageFiles/175158/Summary.pdf>). This

summary includes the most important recommendations of the guideline, and has been developed to create a manageable tool for daily practice. It starts with a brief description of the various phases that can be differentiated during the course of a HIV-infection. This is followed by several generic/preventive recommendations pertaining to absenteeism, returning to work, and individual recommendations extending beyond health care.

**Table 2** *Outline of the guideline ‘HIV and employment’*

Chapter 1	<i>General Introduction</i>	HIV and employment
		Purpose of the guideline
		Target groups
		Composition workgroup
		Methods workgroup
		Scientific evidence
		Realization of the recommendations
		Patients perspective
		Implementation
		Legal implications of the guideline
		References
Chapter 2	<i>Determinants of employment</i>	Introduction
		2.1 Sociodemographic factors
		2.2 Physical and psychological factors
		2.3 Current work status
		2.4 Working conditions
		2.5 Stigma/ discrimination
		2.6 Motivation to work
		2.7 Financial situation
		2.8 Job opportunities
		2.9 Availability of information
		2.10 Other factors
Chapter 3	<i>Disclosure en stigma</i>	References
		Introduction
		3.1 Disclosure
		3.2 Stigma and discrimination
Chapter 4	<i>Interventions</i>	References
		Introduction
		Intervention 1: Rehabilitation program
		Intervention 2: Return-to-work program
		Intervention 3: ‘Project Keep’: Individualized counseling
		Intervention 4: Self-management and transitions in work
		References

Chapter 5	<i>Organization of care</i>	Introduction
		5.1 Prevention of absenteeism in working people with HIV
		5.2 Absenteeism
		5.3 Re-integration
		Preconditions
		5.4 Self-management
		5.5 Communication between careproviders
		5.6 Dissemination
		5.7 Registration
		5.8 Casemanagement
Appendices	<i>Appendix 1</i> <i>Appendix 2</i> <i>Appendix 3</i> <i>Appendix 4</i> <i>Appendix 5</i> <i>Appendix 6</i> <i>Appendix 7</i> <i>Appendix 8</i>  <i>Appendix 9</i>	References
		Themes from focus groups and questionnaires
		Key questions
		Levels of evidence
		Table ‘determinants of employment’
		Stages of HIV
		Legislations around illness and disability
		Usefull links and guidelines
		Overview of professionals from occupational health and curative care
		Dissemination and implementation plan

The following section is an illustration of the results for each key question, with the conclusion of scientific evidence, considerations and the recommendation.

**Key question 1: Which determinants play a role in the employment of people with HIV?**

There is limited evidence (level 3) that the employment of people with HIV is negatively associated with the following socio-demographic factors: female gender, history of captivity, poor housing and the presence of children.<sup>[10, 14, 22, 23]</sup>

The core group believes that, although the level of evidence is low, it is very important, for every patient with HIV, to map out all the socio-demographic factors that may influence employment. This will clarify which factors may stimulate or impede the work participation.

The recommendation is that at an early stage of treatment/ counseling the following socio-demographic factors should be identified: age (a higher age means a lower chance of returning to work), gender (women are more likely to lose their job; more men consider returning to work), socio-demographic situation before the diagnosis (a poor situation reduces the chance of work), education level (a higher education level increases the chance of work), employment status (people who are already unemployed are more likely to remain so), presence of children (children reduce the likelihood of obtaining work), ethnic background (the chance of work depends on levels of integration and mastery of the Dutch language) and lifestyle (an unhealthy lifestyle increases the likelihood of absenteeism).

### ***Key question 2: What is the role of disclosure about HIV in relation to employment?***

There is limited evidence (level 4) that fear of discrimination, maintaining self-esteem, shame, privacy, cultural norm of not complaining, protection of others, characteristics of the working environment, confidentiality and/or geographical distance are factors that may be related to disclosure.<sup>[24-26]</sup>

In practice, disclosure is one of the major dilemmas for people with HIV. Most of these people tend not to disclose their HIV status at work. The core group thinks that an important reason for this is that people with HIV will receive less sympathy than people with other chronic diseases.

A disadvantage of nondisclosure is that living with a secret may influence one's psychological well-being. The recommendation is to provide guidance on disclosure and fear of stigmatization. The occupational health physician, HIV nurse or social worker may fulfill an essential role in this. The choice to disclose is always the prerogative of the employee and can never be mandatory.

### ***Key question 3: To what extent does self-management play a role in relation to the employment of people with HIV?***

No scientific literature was available for this key question

In practice it is clear that the level of self-management determines the patient's role in the counseling. With every chronic disease it is necessary to pay attention to self-management and this is also the case in this employment-related guideline. The patient should be in control as much as possible. Therefore is the recommendation to encourage and support the development of self-management skills so that patients can be in control of their disease, employment and quality of life.

### ***Key question 4: Which interventions are effective in stimulating work participation of people with HIV?***

Four studies about four different interventions were selected from the literature search. These interventions are not comparable and are therefore described separately. One of the interventions is described here.

There is limited evidence (level 3) that the “employment options program” has a positive effect on returning to work for people with HIV.<sup>[27]</sup>

As was mentioned in the conclusions of the described study, a sizeable group did not complete the program. The core group is convinced that this is also applicable for interventions in the Netherlands. It is recommended to pay enough attention to maximum participation and the completion of the program whenever you offer a rehabilitation program for people with HIV. Map potential risk factors for failure.

### ***Key question 5: How should the care around employment-related problems for people with HIV be organized?***

This literature search revealed no studies on the organization of care. Therefore, the answer to this key question is described in a different way. We have chosen to formulate considerations and recommendations, related to organization of care, for three stages in employment-related problems: prevention, absenteeism and returning to work. Furthermore, an overview was made of all healthcare

professionals and other professionals involved.

An example of a recommendation of the stage “prevention” is to refer employees with HIV to the occupational health physician or nurse for a preventive consultation. The aim of this consultation should be mapping the resilience of the employee, the workload he or she can cope with and the potential risk factors for absenteeism. Emphasize the professional confidentiality.

### **Endorsement and publication of the guideline**

Official endorsement of the guideline was provided by all involved professional associations and the Dutch HIV Association. The guideline is digitally published on the websites of the professional associations, the Dutch HIV Association and other websites about HIV and employment, such as [www.positiefwerkt.nl](http://www.positiefwerkt.nl) and [www.kiza.nl](http://www.kiza.nl). The complete text of the guideline is available in Dutch. A summary for daily practice is available in English and Dutch.

## **Discussion**

The multidisciplinary guideline on HIV and employment helps patients with HIV by explaining how they can manage their careers. For healthcare and other professionals it constitutes a clinical, easy-to-use guideline outlining how they can support people with HIV with employment-related questions and issues.

The topics covered by the guideline’s key questions were defined by patients and healthcare professionals through focus groups, through individual interviews with patients, and through questionnaires among healthcare providers. The topics of the clinical questions covered the determinants of employment, stigma, self-management, interventions and the organization of care. The guideline gives an overview of the scientific literature available on these topics and describes the experiences of Dutch experts in this field.

For most of the key questions limited scientific evidence was found. Furthermore, the methodological quality of the articles included was poor. Most were poorly conducted and/ or poorly reported small cross-sectional studies, qualitative studies and narrative reviews. Because there were few longitudinal studies, it was difficult to gain insight into the causal relationship between a determinant and its influence on the employment of people with HIV. The lack of proper evidence from scientific research implied that some of the recommendations are mainly based on the expertise and experience of the multidisciplinary core group in the Netherlands. Therefore more scientific research in this topic, for example on interventions and the organization of care, is needed.

Although we conducted a sensitive search on HIV and employment, the literature search did not reveal any articles about volunteer work and HIV. Nevertheless we acknowledge the importance of volunteer work for people with HIV, and believe that many of the recommendations are applicable to volunteer work as well. Further research on volunteer work and HIV is recommended.

In January 2012 a scoping review was published about the labor-force participation of people with HIV<sup>[28]</sup> This review describes several barriers and facilitators relating to the employment of people

with HIV. The challenges outlined in it are similar to the ones we found in our literature research for this guideline. Furthermore, the conclusion of this study is that labor-force participation will continue to be a key concern for people with HIV and their service providers and policy makers. The guideline can be considered to be one of the support options available for this problem.

As this guideline was developed in the Netherlands, the recommendations it makes should be interpreted within the context of the Dutch health and welfare systems. It is nevertheless important that we share knowledge and best practices about HIV and employment. This guideline is therefore an important step towards exchanging knowledge and best practices, and ultimately towards optimizing the situation regarding the employment of people with HIV. The main concepts of the guideline are also applicable for other Western countries, when adapted for the local situation.

Finally, the generalization of the guideline to make it applicable to other countries is difficult since it is currently only available in Dutch. Therefore the summary for daily practice is available in English. To adapt and translate the guideline for other countries, we would like to encourage international cooperation.

## Conclusion

The guideline gives a unique overview of the scientific literature available on HIV and employment and describes the experiences of Dutch experts in this field. This guideline is the first to be published on HIV and employment, and therefore constitutes an important step in improving the situation of people with HIV as it relates to employment. However, for the future there is a need for high quality quantitative and qualitative research on HIV and employment. Especially intervention studies should be conducted to determine the effectiveness of existing interventions and to develop interventions for promoting a return to work for people with HIV, as well as job retention.

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## Appendix 1: Search terms

### **Search terms on Pubmed (terms were suitably adapted for other databases)**

Search #1 AND #2 Limits: Humans, Publication Date from 1996/01/01 to 2010/09/16

#1 Search “Rehabilitation, Vocational”[Mesh] OR “Employment”[Mesh] OR “Employment, Supported”[Mesh] OR “Work”[Mesh] OR “Sick Leave”[Mesh] OR “Absenteeism”[Mesh] OR “Occupational Health”[Mesh] OR “Occupational Medicine”[Mesh] OR unemployment[tw] OR employee[tw] OR employer[tw] OR vocational\*[tw] OR “work capacity”[tw] OR “work status”[tw] OR “work rehabilitation”[tw] OR “re-employment”[tw] OR underemployment[tw] OR “job retention”[tw] OR “return to work”[tw] OR return-to-work[tw] OR worker[tw] OR ((occupational[tw] OR work[tw] OR employ\*[tw] OR vocational[tw] OR job[tw]) AND rehabilitation[tw]) Limits: Publication Date from 1996/01/01 to 2010/09/16

#2 Search HIV Infections[MeSH] OR HIV[MeSH] OR “Acquired Immunodeficiency Syndrome”[Mesh] OR hiv[tw] OR hiv-1\*[tw] OR hiv-2\*[tw] OR hiv1[tw] OR hiv2[tw] OR hiv infect\*[tw] OR human immunodeficiency virus[tw] OR human immunodeficiency virus[tw] OR human immunodeficiency virus[tw] OR human immune-deficiency virus[tw] OR ((human immun\*) AND (deficiency virus[tw])) OR acquired immunodeficiency syndrome[tw] OR acquired immunodeficiency syndrome[tw] OR acquired immuno-deficiency syndrome[tw] OR acquired immune-deficiency syndrome[tw] OR ((acquired immun\*) AND (deficiency syndrome[tw])) OR “sexually transmitted diseases, viral”[MESH:NoExp] NOT (animal[mesh] NOT human[mesh]) Limits: Publication Date from 1996/01/01 to 2010/09/16

**CHAPTER 3**

The development of a multidisciplinary, evidence-based guideline for “HIV and employment”

# LIVING WITH HIV

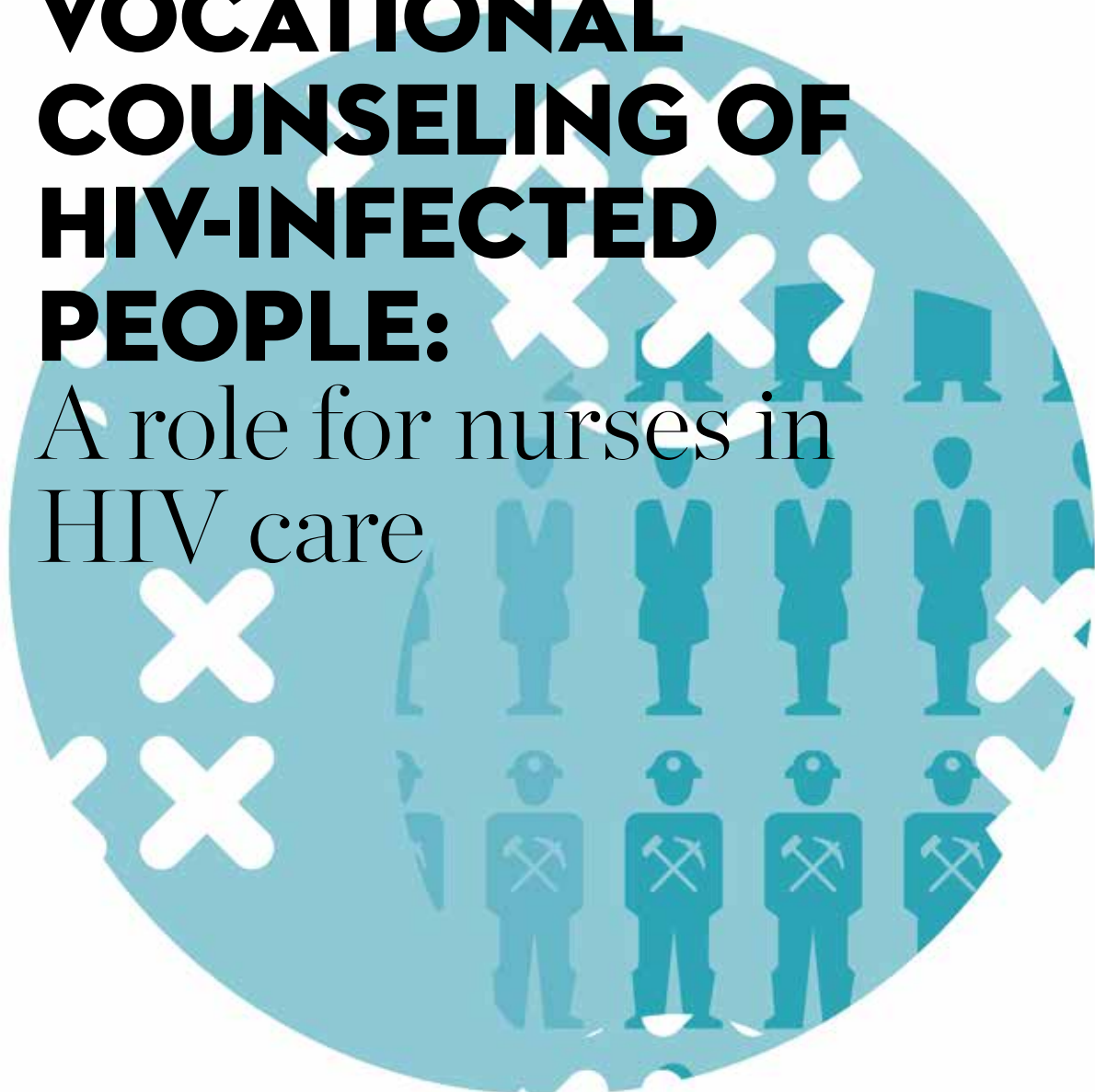
Implications for work participation

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## Chapter 4

# VOCATIONAL COUNSELING OF HIV-INFECTED PEOPLE:

A role for nurses in  
HIV care



### Authors

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### Abstract

People living with HIV (PLWH) face various work-related problems, such as stigma and physical difficulties. Health care professionals can help improve the employment situation of PLWH. Nurses who work in HIV care play a central role in the care of PLWH in the Netherlands. The aim of this cross-sectional study was to investigate the contributions of nurses to the vocational counseling of PLWH, and to make an inventory of needs for future care. Our findings, collected with a self-administered survey, clarified that HIV nurses in the Netherlands regularly faced patients with problems at work, but that they didn't have the required knowledge to provide assistance. Our study emphasized the important role of HIV nurses in vocational counseling because of their central positions in care and their confidential relationship with patients. The study underlined the importance of available, up-to-date knowledge about HIV and work, as well as a clear referral network.

### Key Words

*Employment*

*HIV*

*Nurse*

*Vocational  
counseling*

Since the availability of effective antiretroviral therapy (ART), HIV has become a manageable chronic disease. This implies that people living with HIV (PLWH) not only have to deal with their physical situations, they also have to focus on activities in daily life and participation, such as employment.<sup>[1]</sup> Employment is an important quality of life factor for all people, including those living with chronic diseases. Research on employment in relation to various chronic diseases has shown that work brings social, economic, and emotional benefits.<sup>[2-4]</sup> Reduced work participation leads to fewer financial resources, reduced independence, and a higher prevalence of depression and anxiety disorders.<sup>[5, 6]</sup> The employment rate of people with chronic diseases is significantly lower than that of healthy people.<sup>[7]</sup> In the European Union, about 47% of persons with disabilities are employed compared to 72% of persons without disabilities.<sup>[8]</sup> In the Netherlands, in 2010, a quarter of all chronically ill people had a paid job of at least 12 hours a week compared to 67% of the total labor force.<sup>[6]</sup> Studies in Western industrialized countries and the United States have shown that the unemployment rate among PLWH ranges from 45% to 60%.<sup>[9]</sup>

People with HIV face various problems at work or when returning to work.<sup>[10-12]</sup> Stigma is one of the main issues PLWH face. Lack of knowledge among employers and colleagues is a cause of stigma and discrimination. Furthermore, PLWH often experience physical and psychological complaints such as fatigue, cognitive impairment, and distress. These factors are negatively associated with work participation or productivity at work.<sup>[13-20]</sup> In order to improve vocational counseling for PLWH and to reduce employment-related problems in the Netherlands, a multidisciplinary, evidence-based guideline “HIV and work” was developed.<sup>[21, 22]</sup> This evidence-based guideline consisted of a comprehensive literature review about HIV and work. Based upon the literature and the opinions of experts, recommendations for practice were formulated. One of these recommendations was to discuss issues about HIV and work more thoroughly between patients and various professionals who provide treatment and care, such as the general practitioner, medical specialists for HIV, and nurses who work in HIV care. The consensus among the developers was that health care professionals were able to help improve the employment situation of PLWH. Therefore, attention to employment should be part of everyday clinical practice.<sup>[23]</sup> However, with regard to work-related problems, it remains unclear how different health care providers can address tasks and responsibilities.

In the Netherlands, HIV nurses play a central role in the care of PLWH. They counsel patients on a regular basis and are easily accessible. The HIV nurse supports the HIV-infected patient on a medical and social level, by giving advice, instructing, and consulting. Additionally, HIV nurses enhance the expertise of other care providers by informing them about HIV-specific problems.<sup>[24]</sup> Because of their central position in HIV care in the Netherlands, the HIV nurse is a good candidate for a central role in the vocational counseling of PLWH. Therefore, in the guideline “HIV and work” this role was recommended for the HIV nurse. However, it was unclear if this task would be entirely new for HIV nurses, to what extent it would fit into the competences that nurses had acquired in their educations, and how often nurses were confronted with work-related issues. For this reason, we conducted a cross-sectional study with the primary aim of investigating the current contribution of HIV nurses to vocational counseling for PLWH in the Netherlands. A second aim was to make an inventory of needs and recommendations in HIV nurses to acquire sufficient competences for this task.

## Methods

### Study design

The main goal of this cross-sectional study was to gain insight into the contribution of HIV nurses to vocational counseling for PLWH. We distributed a questionnaire with mainly closed-ended questions to obtain quantitative data. On some topics, if more insight in experiences and opinions was desired, open-ended questions were posed. The open-ended questions were analyzed as qualitative data.

### Participants

Our cross-sectional study was conducted in the Netherlands. We asked 78 nurses, who specialized in adult-care and were stationed in 25 HIV outpatient centers that were all part of the same health care system, to participate in the study. According to the Dutch Medical Research Involving Human Subjects Act (WMO), the study was exempt from medical ethical review. The study complied with the Netherlands Code of Conduct for Scientific Practice from the Association of Universities in the Netherlands.

### Instrument

Data were collected with a self-administered questionnaire, developed by the researchers. When we developed the questionnaire, no other existing questionnaires were available on this novel topic. Therefore, questions were based on the results of a qualitative study with PLWH.<sup>[25]</sup> In that qualitative study, PLWH were interviewed about their experiences with work and addressed relevant themes for PLWH related to work and employment. The themes from that study provided the basis for key questions in the multidisciplinary guideline “HIV and Work”.<sup>[21]</sup> Our study was conducted parallel to the development of the guideline. Furthermore, we reviewed the scientific literature about HIV and employment in the context of the development of the multidisciplinary guideline. The results of this review were also used to develop the questionnaire, and Wagener, Roelofs, et al.<sup>[22]</sup> documented the methodological development of the guideline. Finally, we conducted an exploratory open interview with three nurses in HIV care to inventory their experiences related to HIV and employment.

The compiled questionnaire consisted of 25 questions, including mostly closed-ended and some open-ended questions. Data were obtained for seven domains: participant characteristics, types of work-related concerns, knowledge and skills for work-related concerns, referral to other professionals, collaboration with other HIV nurses, role of the professional association, and quality of counseling by the HIV nurse.

The questionnaire was available in Dutch. The concept questionnaire was sent out for review by other researchers and was pre-tested in a small sample of nurses in HIV care. The questionnaire was adapted based on comments from the pre-test. A list of explanations of the key concepts was added to increase the reliability and validity of the questionnaire. Examples of the questions in every domain are shown in Table 1.



**Table 1 Sample of Questions from the Questionnaire**

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Participant characteristics

Age:

*How many HIV patients do you have under care at this moment?*

---

Types of work-related concerns

*How often in a month are you confronted with a patient with work-related problems?*

Number:

*“What do you do in case of a sickness report due to HIV?” (open question)*

*“Which work-related problems do you meet in practice?” (multiple answers possible):*

- *Concerns about employment impact on health*
  - *Concerns about reduced capability due to fatigue*
  - *Concerns about reduced capability due to reduced cognitive functioning*
  - *Concerns about reduced capability due to side effects of medication*
  - *Concerns about reduced capability due to co-morbidity*
  - *Concerns about employability and career development*
  - *Fear of losing social security*
  - *Fear of disclosure*
  - *Fear of stigma and discrimination by the employer*
  - *Fear of stigma and discrimination by colleagues*
  - *External pressure and the sick role*
  - *Uncertainty about the rights and obligations of the patient*
  - *Lack of facilities at work*
  - *Choice of profession*
  - *Other ...*
- 

Knowledge and skills about work-related concerns

*“I have enough knowledge to support and inform the HIV patient in concerns about reduced capability due to fatigue” Responses: completely disagree, somewhat disagree, neutral, somewhat agree, completely agree*

---

Referral to other health care professionals

*“Do you ever refer to other health care professionals in case of work-related problems, such as the occupational health physician?”*

- *Yes, namely:*
- *No*

*“What professionals would you like to cooperate with on HIV and work?” (open-ended question)*

---

Collaboration with other HIV nurses

*“Does consultation take place between you and other HIV nurses in your clinic?”*

- *Yes, how often:*
- *No*

*“Do you experience these consultations as meaningful?” (open-ended question)*

---

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### Role of the professional association

*“What is your opinion about the amount of attention on HIV and work of the professional association?”*

- *There is much attention on this topic*
  - *There is enough attention on this topic*
  - *There is little attention on this topic*
  - *There is insufficient attention on this topic*
  - *There is no attention on this topic*
- 

### Quality of counseling by the HIV nurse

*How do you rate, on a scale from 1-5, the quality of counseling on work-related problems for people with HIV provided by the HIV nurse?*

- *1 (bad)*
  - *2 (insufficient)*
  - *3 (moderate)*
  - *4 (sufficient)*
  - *5 (good)*
- 

## Procedures

Nurses were invited to participate through the Dutch Association of HIV Nurses, which was also involved in the study. An e-mail explaining study-goals and procedures was sent to all nurses. The questionnaire could be completed anonymously online using the digital survey system “Parantion” (<http://www.parantion.com/website/>). Only the researchers had access to survey responses. In case of non-response, a reminder was sent after 2 and 4 weeks. The inclusion period was July-August 2011.

## Analysis

The main goal of our study was to investigate the experiences of nurses in HIV care with counseling patients about work-related issues. Therefore, the questionnaire consisted of both closed-ended and open-ended questions.

### ***Closed-ended questions***

The closed questions were described using descriptive statistics of SPSS 21 (IBM). Descriptive statistics are presented in the text. For some variables, tables have been created.

### ***Open-ended questions***

Constant comparison<sup>[26]</sup> was used as the basic qualitative analysis method to analyze the answers on open-ended questions. First, all answers were read and key themes were labeled. Subsequently, subcategories were created for a broader understanding of the major themes, and compared with the literature. The findings were summarized; the main findings are described below and suitable quotations are used to illustrate the findings. The results (quantitative and qualitative) are classified and described by the themes of the questionnaire.

# Results

## Participant characteristics

A total of 44 nurses in HIV care participated in the study, which was a response-rate of 56%. As shown in Table 2, the participants were mostly women. This was to be expected because most HIV nurses in the Netherlands are female. The average age was 47 years, and the nurses had worked 8.8 years in HIV care on average for 30.3 hours a week. With regard to education level, all of the nurses had a Bachelor's or Master's degree. On average, the nurses had 330 HIV-infected patients (SD = 252) under supervision. The large standard deviation can be explained by the way respondents interpreted the question. Some respondents mentioned the total number of patients under care in their clinic and others mentioned only their own patients. The nurses saw about 65 HIV-infected patients a month on average.

**Table 2 Characteristics of participating HIV nurses (n = 44)**

Gender	n (%)
Male	7 (15.9)
Female	37 (84.1)
Age in years, mean (SD)	45.6 (8.6)
Education level	n (%)
Intermediate Vocational Education	2 (4.5)
Bachelor	23 (52.3)
Master	18 (40.9)
PhD	1 (2.2)
Number of years working as HIV nurse	mean (SD)
Overall	8.8 (6.5)
0-5	14 (31.8)
6-10	17 (38.6)
11-15	3 (6.8)
> 16	9 (20.5)
Number of working hours a week	30.32 (6.5)
Number of patients under supervision	329.7 (252.3)

## Types of work-related concerns

On average, the HIV nurse was confronted 6.1 times per month with an HIV-infected patient who had experienced work-related problems. Patients usually started talking about work-related problems during consultation hours, but sometimes also did so by email or telephone. Almost all the HIV nurses (86%) registered patient work status (employed/unemployed, full-time/part-time, occupation) and patient work history. When a patient reported work-related problems this was also noted (93%), mostly in the digital patient record.

Most of the nurses wanted to know the reason for absenteeism. They wanted to know if HIV or an HIV-related complication was the cause of a need to be absent from work and if intervention was possible. In cases of short-term absenteeism, patients were usually not referred to other professionals. However, in cases of long-term absenteeism, the nurses also wanted to know the patient's relationship with work and if intervention needed to be recommended by, for example, an occupational health physician. Fear of stigma, discrimination, and disclosure were the main work-related issues that HIV-infected patients reported to the nurses. Furthermore, concerns about diminished capacity caused by fatigue and medication side effects were important issues for HIV-infected patients with regard to work. In Table 3, all work-related concerns brought up by patients are listed.

**Table 3** *Types of work-related concerns*

Concerns	N (%)
Concerns about employment impact on health	35 (79.5)
Concerns about reduced capability due to fatigue	42 (95.5)
Concerns about reduced capability due to less cognitive functioning	17 (38.6)
Concerns about reduced capability due to side-effects of medication	41 (93.2)
Concerns about reduced capability due to co-morbidity	20 (45.5)
Concerns about employability and career development	28 (63.3)
Fear of losing social security	28 (63.6)
Fear of disclosure	42 (95.5)
Fear of stigma and discrimination by the employer	43 (97.7)
Fear of stigma and discrimination by colleagues	43 (97.7)
External pressure and the sick role	19 (43.2)
Uncertainty about the rights and obligations of the patient	32 (72.7)
Lack of facilities at work	17 (38.6)
Choice of profession	21 (47.7)

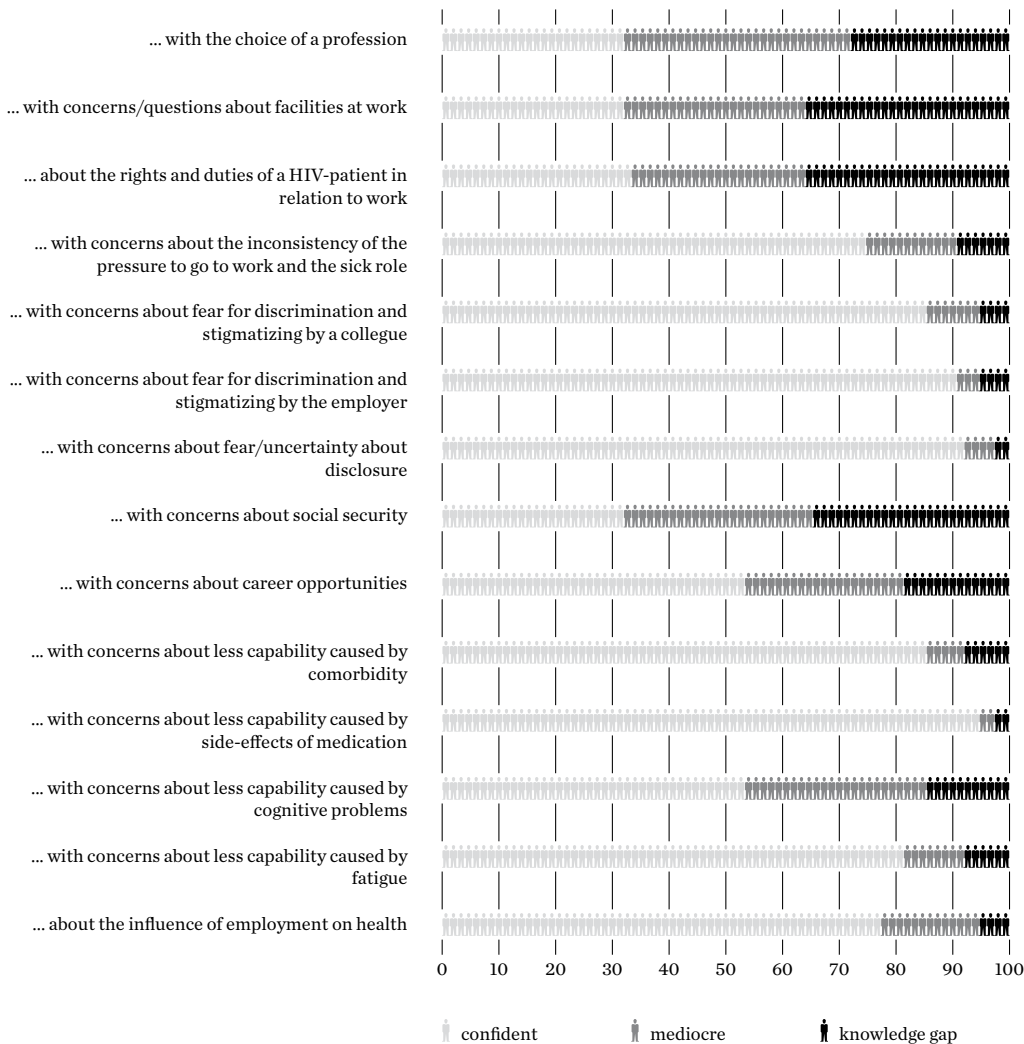
**Knowledge about work-related concerns**

HIV nurses were asked if they thought they had enough knowledge about work-related problems. As shown in Figure 1 the response was positive on many of the related issues. However, knowledge about social security, rights, and duties (e.g., when on sick leave or when applying for a job) was felt to be lacking. The nurses also indicated that they felt less competent advising patients about facilities at work, career opportunities, or choice of profession. About half of the nurses did not feel sufficiently secure to help patients with concerns about decreasing capabilities due to cognitive problems. In one open-ended question, the nurses were asked to describe issues an HIV nurse should have knowledge of in order to provide proper consultation when work-related problems were presented. One of the respondents said:  
“Obviously, we need to have knowledge of the physical and psychological impact of HIV diagnosis and be able to monitor this individually. Patients respond so diversely, even to medication side effects. We

have to know the rights and duties and should be able to find information, and much more . . .”  
Having knowledge of HIV and the impact of the disease on daily functioning was one important theme. Another important theme was related to legal rights and duties, for the employee as well as the employer. As one respondent answered: “I am barely aware of rights and obligations for patients. This makes it difficult to act as intermediary.”

**Figure 1 Knowledge about work-related issues.**

**I HAVE ENOUGH KNOWLEDGE TO SUPPORT AND INFORM THE HIV-PATIENT**



Referral options were mentioned, as well as the role of stigma and side effects of medication. Good communication, conversation, and advisory skills were described as skills that nurses in HIV care needed to help patients deal with work-related problems.

**Referral to other professionals**

Some respondents had doubts about the role of the HIV nurse in vocational counseling and thought that the nurse's only function was to refer. Training or a handbook about HIV and work, and a clear referral network were mentioned as being helpful for good counseling.

Most respondents referred to the occupational health physician when a patient expressed severe work-related concerns. The main reason for this was that the occupational health physician had professional confidentiality and knowledge about employability. Satisfaction with these contacts varied. "I usually first recommend the patient to involve the occupational health physician, also because of his professional confidentiality. Unfortunately, I sometimes hear that patients cannot rely on this. There is no real cooperation." Patients were sometimes referred to a social worker, especially in cases of financial problems.

**Collaboration with other nurses in HIV care**

Seventy-three percent of the nurses in our study had regular consultation with other HIV nurses in the same hospital about the work-related concerns of their patients. These consultations were always experienced as meaningful. Consultations with nurses from other hospitals about work-related concerns were also used at times (23%). Another 25% of the respondents stated that they would like to have consultations with more experienced HIV nurses in other hospitals.

**Role of professional association of HIV/AIDS nurses**

The opinions on the role of the Professional Association of HIV/AIDS Nurses varied: 32% of the respondents indicated that the association paid enough attention to work-related concerns of HIV-infected patients, but 39% noted that the association should be more active. When asked about the availability of training about HIV and work organized by professional organizations, a quarter of the respondents stated that this topic was not offered, 18% indicated that training has been offered, and about 50% had no opinion. Development of training, professional guidelines, and social maps with referral options were mentioned as possible activities that could be organized.

**Quality of counseling by the HIV nurse**

Two thirds of the respondents rated the quality of counseling by the HIV nurse in case of work-related concerns as sufficient; another 23% rated the quality as moderate. As options for improving the care for HIV-infected workers and consultation in case of work-related problems, nurses in HIV care mentioned: (a) enhance the knowledge of occupational health professionals about HIV, (b) develop a training for nurses in HIV care about all aspects involved in vocational guidance for HIV-infected people, (c) raise awareness about various referral options for nurses, and (d) stimulate/facilitate social acceptance for HIV-infected workers in employers and employees.

## Discussion

In this study we focused on the contribution of nurses in HIV care to the vocational counseling of PLWH. We found that HIV nurses in the Netherlands regularly faced patients with problems at work. Fear of stigma, discrimination, and disclosure were the main work-related issues reported by HIV-infected patients in contacts with the nurses. Furthermore, concerns about limited capability caused by fatigue and side effects of medications were important issues for HIV-infected patients with regard to work. These findings were similar to findings from previous studies<sup>[10, 20]</sup> and support the qualitative research findings of the multidisciplinary guideline on HIV and Work.<sup>[25]</sup>

The nurses in our study stated that their knowledge about work-related problems was not sufficient. Nurses in HIV care experienced gaps in their knowledge and competences with regard to a number of work-related topics. Knowledge about social security, rights, and duties, for instance when on sick leave or when applying for a job, was felt to be lacking. The nurses also indicated that they felt less competent advising patients about facilities at work, career opportunities, or choices of professions. As described in several studies on interventions with the aim to improve work participation, addressing work participation in interventions for people with a chronic condition is beneficial.<sup>[19, 27]</sup> Additional training on work and health could be provided for the nurses in HIV care to support their roles in the guidance of PLWH on work-related concerns.

However, some respondents had doubts about the role of the HIV nurse in vocational counseling and thought that the nurse only had a responsibility to refer. In our opinion, the nurse in HIV care is a key professional in this guidance. Because of nurses' central position in care and their confidential relationships with patients, they can provide important vocational guidance, including that of referrer. Therefore, they should have basic knowledge about HIV and work and various local referral options. A firm recommendation for practice is that a clear referral network be created in order to facilitate cooperation and to make the responsibilities and qualities of all other involved professionals clear. The professional association could incorporate competencies with regard to work-related problems in the job profile of HIV nurses and develop specialized training to support them in the performance of these tasks. In nurses' current job descriptions, no specific attention is paid to work-related problems. In this respect the job-profile of the nurse in HIV care in the Netherlands is comparable to that in other countries. It includes more general competencies, such as contribution to multidisciplinary work and recognition of the impact of HIV stigma on PLWH, but does not mention specific work-related duties. The addition of competencies to assess participation in work activities would help nurses pay more holistic attention to the daily lives of PLWH.

On the other hand, many of the findings in this study were not HIV specific, but are part of living with any chronic disease. Research has shown that self-management skills are essential to manage a chronic disease. Self-management encompasses three elements: medical management, role management (i.e., work participation), and emotion management.<sup>[28]</sup> Interventions that aim to improve self-management skills are essential to increase work participation for people with a chronic condition, including HIV.<sup>[29, 30]</sup> The nurse in HIV care could play an important role in improving the self-management skills of PLWH.

**Reflections on the method**

The moderate response rate of 56% should be mentioned as a limitation of the study. One of the reasons for this might be that the study was conducted during the summer months. We have no information about differences between responders and non-responders. Furthermore, there might have been self-selection (in or out) by responders due to the subject of the study. It is possible that nurses who already pay attention to work-related problems were more willing to complete the questionnaire. As a consequence it is likely that the number of nurses in HIV care who supported work-related counseling as part of their tasks and the competences with regard to vocational counseling were overestimated.

Because this study was conducted in the Netherlands, the results and recommendations may not generalize to other countries. In the Netherlands, an HIV nurse is present in every outpatient clinic and, because of this central position, a role in vocational counseling seems crucial. Whether the results are applicable to other countries depends on local health care systems and situations. In the United States, for example, rehabilitation professionals play an important role in the vocational guidance of PLWH (Hergenrather, Rhodes, & Clark, 2005). However, the nurse in HIV care has also a central position in counseling PLWH in the United States and may, therefore, also be involved in vocational guidance.

## Conclusion

Our study emphasized the important role of nurses in HIV care in vocational counseling because of their central position in care and their confidential relationships with PLWH in the Netherlands. Because work-related problems are a considerable issue for PLWH, the possibilities of the HIV nurse in vocational counseling should be further investigated. In order to develop this role, available up-to-date knowledge about HIV and work, and a clear referral network are needed.

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The authors report no real or perceived vested interests that relate to this article that could be construed as a conflict of interest.



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### Key Considerations

- Nurses in HIV care should play a central role in vocational counseling for people living with HIV (PLWH).
- It is important to define the responsibility of every professional involved in the counseling of PLWH for work-related concerns.
- Up-to-date knowledge about HIV and work, and a clear referral network are essential to provide proper counseling.

**CHAPTER 4**

Vocational counseling of HIV-infected people; A role for nurses in HIV care

# LIVING WITH HIV

Implications for work participation

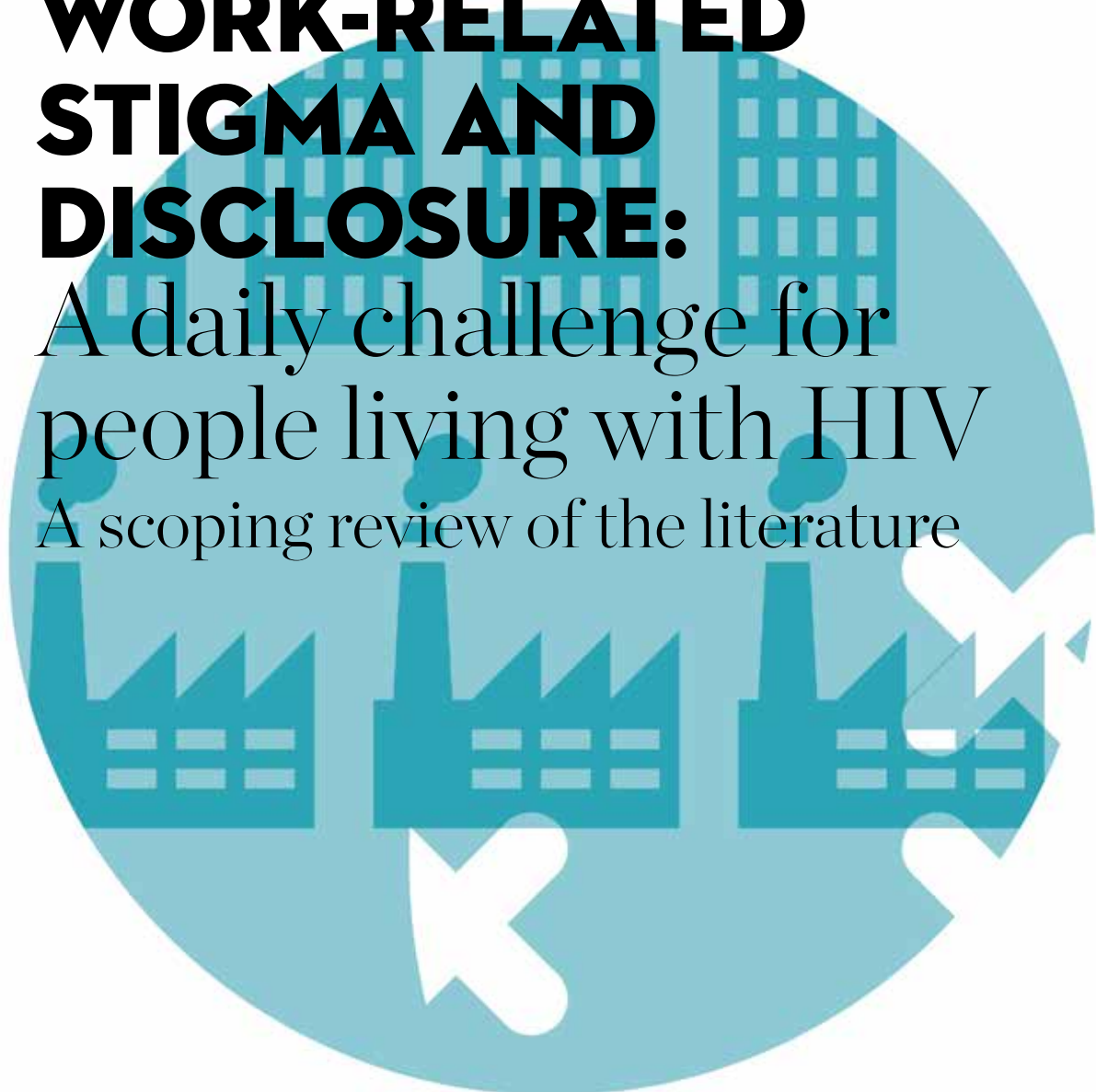
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## Chapter 5

### **WORK-RELATED STIGMA AND DISCLOSURE:**

A daily challenge for  
people living with HIV

A scoping review of the literature



### Authors

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### Abstract

**BACKGROUND** Stigma and disclosure are important work-related issues for people living with HIV (PLWH). To gain better understanding and improve the position of PLWH in the labor market, further insight in these issues is needed.

**OBJECTIVE** This study reviews the scientific evidence related to work-related stigma and disclosure.

**METHODS** A sensitive literature search was performed in the databases of Medline, Embase, Cochrane Library, Cinahl and Psychinfo for articles published between 1996 and 2016. All studies on PLWH in Western countries and investigating disclosure or stigma in relation to work were included.

**RESULTS** Of the 866 identified studies, 19 met the inclusion criteria: 4 addressed both disclosure and stigma (2 quantitative), 9 addressed only disclosure (4 quantitative) and 7 studies addressed only stigma (4 quantitative).

**CONCLUSION** This review provides a unique overview of the research on work-related disclosure and stigma, which will enable health care providers to support PLWH to make well-considered decisions. However, the available literature was heterogeneous and in most studies the topics of our interest were secondary outcomes and provided only basic insight.

### Key Words

Work  
participation

Working  
conditions

Depression

Anxiety

Counseling

## Introduction

Living with HIV as a chronic disease is associated with psychological and social problems, such as HIV-related stigma. Stigma is a discrediting social label that changes the way persons view themselves and the way they are viewed by others.<sup>[1]</sup> Stigma can lead to social exclusion and depression among people living with HIV (PLWH).<sup>[2]</sup> Moreover, a higher prevalence of depression and anxiety is reported among PLWH compared with both the general population and with patients experiencing other chronic diseases.<sup>[3, 4]</sup> Among the population of PLWH, over half experience some type of stigma.<sup>[4]</sup> Due to the fear of stigma, disclosure has become an important issue to be taken into account. Unfortunately, fear of stigma and social exclusion are important reasons for nondisclosure.<sup>[5]</sup>

Disclosure of HIV diagnosis is a complex issue in daily living, with a considerable impact on the quality of life of PLWH.<sup>[6]</sup> The advantages of disclosure include safer sex, better (mental) health, more social support, and increased adherence to antiretroviral therapy<sup>[7-9]</sup>, whereas the negative aspects of disclosure can include rejection, loneliness, stigma and discrimination.<sup>[10]</sup>

The dilemma of disclosure and stigma plays an important role in various social interactions, including sexual relations, family, health care, and work. Because the vast majority of PLWH is of working age, it is important to investigate work-related disclosure and stigma. Of nurses working with HIV patients, 98% reported that the dilemma of disclosure was an important work-related issue of PLWH in their clinics.<sup>[11]</sup> People who experienced HIV-related discrimination had an increased risk of employment loss.<sup>[12]</sup> Also, in the workplace, PLWH may be confronted with gossip, contempt and social isolation from co-workers and/or employers.<sup>[13]</sup>

Participation in the labor force is a key concern for many PLWH.<sup>[14, 15]</sup> However, PLWH still have a lower employment rate than the general population in several European countries<sup>[16, 17]</sup>, and face various problems at work or when returning to work.<sup>[18]</sup>

With the aim to improve vocational counseling, in 2012 a multidisciplinary, evidence-based guideline on HIV and work was developed in the Netherlands.<sup>[19]</sup> This guideline provided recommendations for PLWH and for healthcare providers about how work-related care can be improved. Qualitative research conducted in the context of the guideline development, showed that disclosure and stigma were major work-related concerns of PLWH in the Netherlands.<sup>[15]</sup> However, little scientific evidence/related data were available.

Therefore, stigma and disclosure as barriers for sustainable work participation among PLWH needs additional study to elucidate the daily issues experienced by these individuals in Western countries and to improve counseling methods. Therefore, this review focuses on the scientific evidence for stigma and disclosure at the place of work.

## Methods

A scoping review of the literature was conducted to summarize the findings on stigma and/or disclosure in relation to work. This study was guided by the Arksey and O'Malley framework for scoping studies.<sup>[20]</sup>

## **Identification of studies**

### ***Types of studies***

Included were qualitative and quantitative studies reporting original data on stigma and/or disclosure related to work among adults with HIV, conducted in a Western country. Excluded were case reports, conference proceedings, books, dissertations, and letters to the editor. There were no restrictions on the language of publication.

### ***Search methods***

A literature search was performed in February 2016 in the databases Medline, Embase, Cochrane Library, Cinahl and Psycinfo using a combination of the following keywords (and their synonyms): employment, HIV, stigma, and disclosure. The complete search strategy can be found in Appendix 1. The search was limited to articles published after 1996 because of the introduction of HAART (Highly Active Antiretroviral Therapy) after that date.

### **Selection of studies**

After conducting the search, two authors (MW and SvO) independently screened all search results. First, relevant articles were selected by screening titles and abstracts. Subsequently, we retrieved full-texts of all included articles and the two authors screened these remaining articles for eligibility. Any dissensus was resolved through discussion, or through recourse to an independent author (PR).

### **Data extraction**

Data were extracted directly from the full-text articles by the first author (MW). A pre-structured form was used covering the research design, the main topic of the study (stigma and/or disclosure), sample description, and key findings of each study.

### **Collating, summarizing and reporting results**

Data were classified by the two main themes, i.e. disclosure and stigma. Data on disclosure were divided into subsections (the reported levels of disclosure, background characteristics, reasons for (non) disclosure and consequences of disclosure) in order to integrate the available evidence for each topic. Data on stigma were divided into the following subsections: level of perceived stigma, reported reasons for stigma, background characteristics related to stigma, fear of stigma, and consequences of stigma.

## **Results**

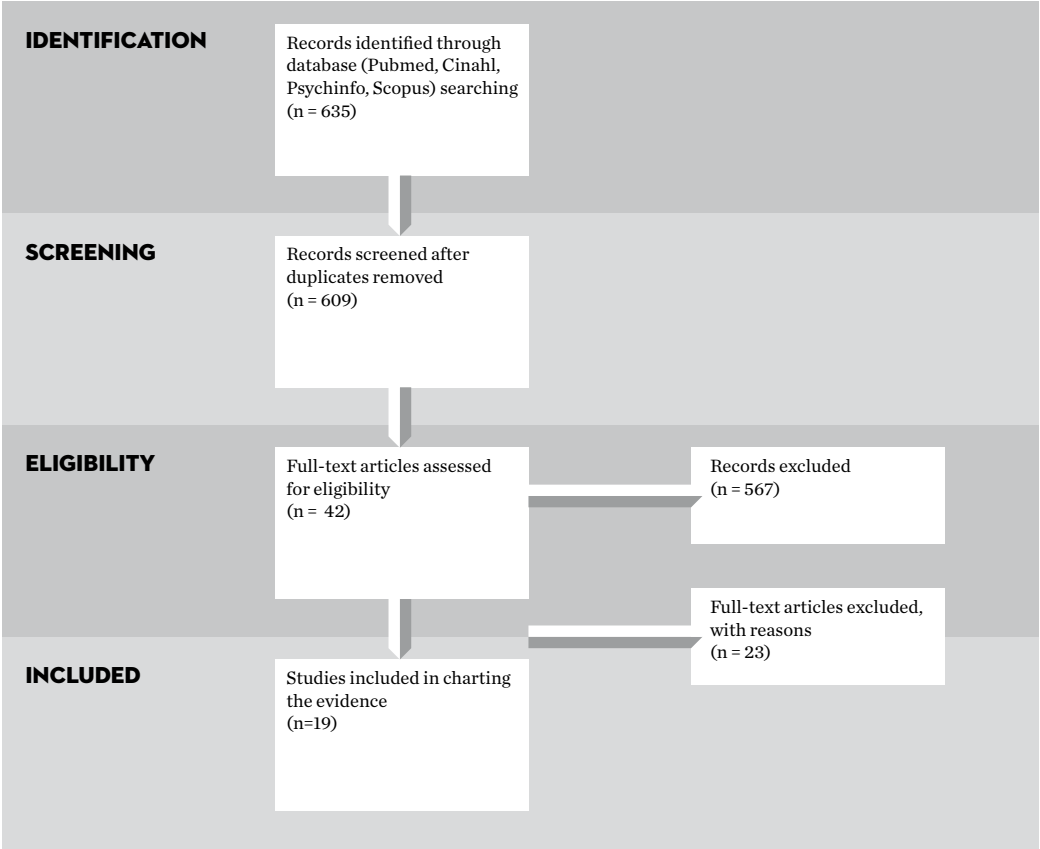
### **Selection of studies**

Figure 1 presents the flow-chart of the selection process. Of the 866 citations retrieved from the search, most were excluded because they did not address work-related problems. A total of 19 studies



met the inclusion criteria: 4 addressed both disclosure and stigma (2 quantitative), 9 addressed only disclosure (4 quantitative) and 7 studies addressed only stigma (4 quantitative). In 30% of the eligible studies, disclosure and/or stigma was not the main focus of the study.

**Figure 1 Selection of the eligible studies**



**Disclosure**

Table 1 summarizes the main findings of the studies on disclosure, which are briefly described below.

Table 1 Main findings of the studies on disclosure.

Author, date, country of origin	Design/ method	Was disclosure in relation to work the main focus of the study?	Sample	Key findings (related to our research question)
Quantitative studies				
Conyers, L. and Boomer, K. 2005 USA	Quantitative: questionnaire	Yes	N=84	<ul style="list-style-type: none"><li>• Level of disclosure to employer: 27%</li><li>• Level of disclosure to employer among people using job accommodations: 33%</li><li>• Factors predicting disclosure: number of years with HIV and the degree to which HIV interfered with their ability to work.</li></ul>
Degroote, S. et al, 2014 Belgium	Quantitative: questionnaire	Yes	N=54	<ul style="list-style-type: none"><li>• Level of disclosure: 50%</li><li>• Reasons for non-disclosure: fear of social and professional consequences</li><li>• Reasons for disclosure: changing health state, absences, desire to be honest, not to live with a secret</li><li>• Participants with a professional, managerial or administrative job were significantly more likely to disclose than participants having manual labour (p &lt;0.05). Level of significance not further specified.</li><li>• Disclosure was not associated with other factors (gender, age, time since diagnosis, disclosure to environment, P&gt;0.05).</li></ul>
Elford, J. et al, 2008 UK	Quantitative: Questionnaire	No	N=1407	<ul style="list-style-type: none"><li>• Level of disclosure to employer: 21.6 %</li><li>• Level of disclosure to colleagues: 29.9%.</li><li>• Less disclosure to employer among ethnic minority gay men and black African heterosexual men and women than white gay men.</li><li>• Reasons for non-disclosure: fear of discrimination at work and anxiety of losing a job.</li></ul>

Escovitz, K. and Donegan, K., 2005 USA	Quantitative and qualitative: intervention study	No	N=148	<ul style="list-style-type: none"><li>• Most participants did not disclose on the job.</li><li>• Reasons for disclosure: seeking accommodation on the job or the feeling to be authentically themselves on the job.</li></ul>
Rodger, A.J. et al 2010 UK	Quantitative: questionnaire	No	N=545	<ul style="list-style-type: none"><li>• Level of disclosure: 37%</li><li>• Those of black African ethnicity were less likely to have disclosed status.</li></ul>
Torres-Madriz, G. et al, 2011 USA	Quantitative: questionnaire Medication Event Monitoring Systems, medical records	No	N=69	<ul style="list-style-type: none"><li>• Level of disclosure to employer: 30%</li><li>• Level of disclosure to co-workers: 48%</li><li>• Consequence of disclosure: accommodations at work</li></ul>
<i>Qualitative studies</i>				
Anderson, M. et al 2008 Caribbean UK	Qualitative: individual semi-structured interviews	No	N=25	<ul style="list-style-type: none"><li>• Selective disclosure: main chosen strategy to avoid stigma and discrimination.</li></ul>
Brooks, R.A, Klosinski, L, 1999 USA	Qualitative: focus group interviews	No	N=30	<ul style="list-style-type: none"><li>• Reasons for non-disclosure: fear and anxiety related to application, treatment by coworkers, ability to advance in a job)</li><li>• Disclosure sometimes necessary, ie.to deal with their health condition.</li></ul>
Emlet, C.A. 2006 USA	Qualitative: structured individual interviews	No	N=88	<ul style="list-style-type: none"><li>• Option: selective disclosure</li><li>• Younger respondents were more concerned about losing their job after disclosure than the older respondents.</li><li>• Disclosure was significantly and positively correlated with time since first HIV diagnosis (<math>p &lt; 0.01</math>), the use of HIV-related services (<math>p &lt; 0.01</math>), having a confidant to talk to (<math>p &lt; 0.01</math>) and negatively correlated with being African American (<math>p &lt; 0.01</math>) and being exposed to HIV through heterosexual contact (<math>p &lt; 0.05</math>). Correlation and significance level not further specified.</li></ul>

Author, date, country of origin	Design/ method	Was disclosure in relation to work the main focus of the study?	Sample	Key findings (related to our research question)
Quantitative studies				
Fesko, S. 2001 USA	Qualitative: open individual interview	Yes	N=18	<ul style="list-style-type: none"><li>• Level of disclosure to everyone in workplace: 30%</li><li>• Women less likely to disclose</li><li>• Reasons for non-disclosure: fear of stigmatization and privacy. Consequence of non-disclosure: social isolation.</li><li>• Main reason to disclose: progression of illness, personal acceptance, risk factors at work.</li></ul>
Wagener, M.N. et al, 2014 The Netherlands	Qualitative: focus group interviews and individual interviews	No	N=27	<ul style="list-style-type: none"><li>• Reasons for non-disclosure: privacy, not relevant for work, fear for stigma (main reason)</li><li>• Some participants were not sure whether they were obliged to disclose at work.</li><li>• Most participants who disclosed, only disclosed partly.</li></ul>

***Level of disclosure***

The level of disclosure to employers/colleagues was reported in six studies and ranged from 22-50%.<sup>[21-26]</sup> In two studies a comparison was made between employers and colleagues<sup>[21]</sup>; the conclusion was that the level of disclosure to the employer is lower than that to colleagues (22-27% vs. 30-33%). One study showed that most participants only partly disclosed to a few people at their work.<sup>[15]</sup>

***Background characteristics associated with disclosure***

In six studies background characteristics were reported as factors associated with disclosure, i.e. age, gender, ethnicity, disease-related factors, and characteristics of the workplace<sup>[21-26]</sup>; these are described below.

***Age***

One study reported the role of age in relation to disclosure and concluded that disclosure was not associated with age ( $p > 0.05$ ).<sup>[22]</sup>

***Gender***

The role of gender was reported in two studies. One study found no difference<sup>[22]</sup>, whereas the other concluded that women were less likely than men to disclose their HIV-positive status at the work place.<sup>[24]</sup>

***Ethnicity***

Three studies investigated ethnicity<sup>[23, 25, 27]</sup>; all concluded that a black African ethnic background was associated with a lower level of disclosure.

***Disease-related factors***

Three studies reported on the role of time since diagnosis in relation to disclosure<sup>[21, 22, 27]</sup>; two of concluded that disease duration and number of years with HIV were associated with a higher level of disclosure<sup>[21, 27]</sup>. The odds ratio for disclosure to the employer increased with 43% for each additional year ( $p < 0.05$ ).<sup>[21]</sup> One study reported the influence of the way of transmission, concluding that being exposed to HIV because of heterosexual contact is negatively associated with disclosure.<sup>[27]</sup>

***Characteristics of the workplace***

Two studies reported characteristics of the workplace.<sup>[21, 22]</sup> Both concluded that a higher position in the organization (e.g. managers) or non-manual work (e.g. professional or administrative) were positively associated with the level of disclosure. Furthermore, the degree to which HIV interfered with one's ability to work was an important predictor of disclosure.<sup>[21]</sup>

***Reasons for disclosure***

The reasons for disclosure were divided into four subgroups: personal, work-related, changing health status, and relation with colleagues or employer.

## CHAPTER 5

Work-related stigma and disclosure: a daily challenge for people living with HIV

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### *Personal reasons*

Three articles described different personal reasons for disclosure, such as not wanting to live with a secret and honesty<sup>[22]</sup>, personal acceptance of the HIV status<sup>[24]</sup>, and the need to be accepted without prejudice.

### *Work-related reasons*

The need for accommodation and support at work was mentioned in two studies.<sup>[24, 28]</sup> Furthermore, the need to provide an explanation for choices regarding work, and concerns about workability, were important reasons to disclose HIV status at work.

### *Changing health status*

Three studies reported that disclosure is sometimes necessary because of a change in health status, such as progression of the illness which may lead to absences.<sup>[22, 24, 29]</sup>

### *Relation with colleagues and employer*

One study examined the level of trust in colleagues and employer and found this to be an important aspect in the decision to disclose.<sup>[30]</sup>

### ***Reasons for non-disclosure***

The reasons for non-disclosure can be divided in two groups: need for privacy, and fear of stigma.

#### *Need for privacy*

Two studies reported that the main reason for concealment of the HIV status at work was the need for privacy.<sup>[24, 28]</sup> One study concluded that the perceived irrelevance of the HIV status for work was important for the decision not to disclose.<sup>[15]</sup>

#### *Fear for stigma*

Five studies described that fear of stigma is one of the main reasons for non-disclosure.<sup>[24, 25, 28-30]</sup> Also limited disclosure (to only one, or a few colleagues) can be an important strategy to avoid stigma.<sup>[30]</sup>

### ***Consequences of disclosure***

After the decision to disclose or conceal their HIV status PLWH faced different consequences, varying from more accommodations at the workplace<sup>[26]</sup> to social isolation<sup>[24]</sup> or gossiping.<sup>[15]</sup>

## **Stigma**

Table 2 summarizes the main findings of the studies on stigma; these are briefly discussed below.

Table 2 Main findings of the studies on stigma.

Author, date, country of origin	Design/ method	Was stigma in relation to work the main focus of the study?	Sample	Key findings (related to our research question)
<i>Quantitative studies</i>				
Brooks, R.A et al. 2004 USA	Quantitative: questionnaire	No	N=1991	<ul style="list-style-type: none"><li>• Barriers to employment: fear that co-workers dis cover the HIV-status and concerns about HIV/AIDS related discrimination.</li></ul>
Chan, F. et al. 2005 USA	Quantitative: descriptive	Yes (although focused on several disabilities)	N=35.763 (allegations)	<ul style="list-style-type: none"><li>• 2610 filed allegations (7.3%) of HIV/AIDS workplace discrimination.</li><li>• The top four of allegation were: discharge (47%), terms and conditions (11%), harassment and reasona- ble accommodation (11% each)</li></ul>
Liu, Y. et al, 2012 China and USA	Quantitative: Interview	Yes (employers)	N=156	<ul style="list-style-type: none"><li>• Predictors of employers' intent to interview: fear of contagion and perceived incompetence (<math>p&lt;.0.05</math>).</li></ul> Level of significance not further specified.
Marsicano et al, 2014	Quantitative: questionnaire	No	N=3022	<ul style="list-style-type: none"><li>• Reported discrimination: 24% (when applying for a job), 6% (at work)</li><li>• Migrant women (<math>p&lt;0.01</math>, OR 16.09, CI [3.00,86.22]), migrant men (<math>p&lt;0.05</math>, OR 7.39, CI [1.15,47.38]), MSM (<math>p&lt;0.05</math>, OR 5.57, CI [1.12,27.79]), non- African women (<math>p&lt;0.05</math>, OR 7.01, CI [1.27,38.62]), and female drug users (<math>p&lt;0.1</math>, OR 12.93, CO [0.96,174.27]) experience more discrimination at work than heterosexual men</li><li>• People older than 55 reported more discrimination when applying for a job (<math>p&lt;0.05</math>, OR 2.13, CI [1.18, 3.86]).</li><li>• High education level was associated with more dis- crimination at work (<math>p&lt;0.05</math>).</li></ul>

Author, date, country of origin	Design/ method	Was stigma in relation to work the main focus of the study?	Sample	Key findings (related to our research question)
Quantitative studies				
Rodger, A.J. et al 2010 UK	Quantitative: questionnaire	No	N=545	<ul style="list-style-type: none"><li>• People with a paid job did not report stigma</li><li>• For those not working stigma was a major concern (83%)</li></ul>
Torres-Madriz, G. et al, 2011 USA	Quantitative: questionnaire, Medication Event Monitoring Systems, medical records	No	N=69	<ul style="list-style-type: none"><li>• Level of perceived stigma: 10% reported discrimination at the work place.</li><li>• 69% were allowed to go to appointments</li><li>• 34% lost pay for going to medical appointments</li></ul>
Wagener M.N. et al, 2015 The Netherlands	Quantitative: questionnaire among HIV nurses	No	N=40	<ul style="list-style-type: none"><li>• Main work-related issue for PLWH: fear of stigma by employers and colleagues (reported by 98% of the HIV nurses)</li></ul>
Qualitative studies				
Anderson, M. et al 2008 Caribbean UK	Qualitative: individual semi-structured interviews	No	N=25	<ul style="list-style-type: none"><li>• Consequences of stigma and discrimination: undermining care and treatment, and limiting opportunities for integration into society and economic independence.</li></ul>
Brooks, R.A, Klosinski, L, 1999 USA	Qualitative: focus group interviews	No	N=30	<ul style="list-style-type: none"><li>• Consequences of stigma: not pursuing certain types of jobs.</li><li>• Many felt that most employers would not be HIV sensitive.</li><li>• Most participants thought that the Americans with disabilities Act would not protect them from discrimination.</li></ul>



Dubois-Arber, F. et al. 2001 Switzerland	Qualitative: legal texts, internal regulations, interviews with key informants, testimonials of persons living with HIV/AIDS.	No	N=200 (expert interviews) M=82 (testimonials)	<ul style="list-style-type: none"><li>• No discrimination was found in legal texts or regulations in the two cantons studied. However, stigmatisation and practices of individual discrimination persist.</li></ul>
Rao, 2008 USA	Qualitative: semi-structured, interview	Yes	N=100 (employers)	<ul style="list-style-type: none"><li>• In all three cities there was a general reluctance to hire people with HIV (more pronounced in Beijing and Hong Kong).</li><li>• Employers appeared to have concerns about the contagiousness (biological and social) of HIV/AIDS.</li></ul>
Serrano, A. 2015 Canada	Qualitative: in-depth interviews	No	N=30	<ul style="list-style-type: none"><li>• 13.3% of the migrant Latino's reported HIV-stigma at work as a barrier to employment.</li></ul>
Wagener, M.N. et al, 2014 The Netherlands	Qualitative: focus group interviews and semi-structured interviews	No	N=27	<ul style="list-style-type: none"><li>• Participants reported fear of stigma at work</li><li>• Some participants who disclosed at work experienced stigma (i.e. gossip)</li><li>• Reason for stigma: lack of knowledge</li><li>• Disclosing their HIV-status would be the only way to reduce stigma.</li></ul>

***Level of perceived stigma***

Three studies reported the level of perceived stigma at work; this ranged from 6-11%.<sup>[25, 26, 31]</sup> One study reported that over two-thirds of PLWH reported that they were not allowed to go to a medical appointment during working hours without losing payment, which might be considered as stigma.<sup>[26]</sup> Another study reported that 24% of their participants indicated facing discrimination when applying for a job.<sup>[31]</sup> One study made an analysis of the complaints submitted to the Equal Employment Opportunity Commission about discrimination at work because of a chronic disease (including HIV): of all complaints filed by people with disabilities under the employment provisions of the Americans with Disabilities Act in the period 1992-2003, 7.3% concerned discrimination of PLWH. The most important reasons for complaints were resignation, a change of contract, harassment, or not being offered work accommodations.<sup>[32]</sup> In a Swiss study, no discrimination was found in legal texts or regulations. In contrast, stigmatization and practices of individual discrimination seems to be present based on interviews with informants.<sup>[33]</sup>

***Reported reasons for stigma***

Several reasons for stigma and discrimination emerged, including fear of contamination, lack of awareness, homophobia<sup>[30]</sup>, and the general perception that it is a person's own fault that they are HIV positive.<sup>[24]</sup> In two other studies all employers indicated having difficulties when hiring PLWH, because of their concerns about possible biological and/or social contagion.<sup>[34, 35]</sup>

***Background characteristics related to stigma***

Older people, men who have sex with men, drug users and migrant women experienced significantly more discrimination.<sup>[31]</sup> A comparative study of PLWH in different geographical regions concluded that work-related stigma and discrimination appeared more often and was more severe in the Caribbean area than in the UK.<sup>[30]</sup>

***Fear of stigma***

In four studies fear of stigma was also described, but without a relation to (non) disclosure. Three studies noted that, for people currently not working, fear of being stigmatized by colleagues was a major barrier to obtaining employment.<sup>[25, 29, 36]</sup> The other study described the perception of many participants, that employers are not HIV sensitive and that the Americans with Disabilities Act would not protect them from discrimination.<sup>[37]</sup> In another study, 98% of HIV nurses reported that fear of stigma was one of the main work-related issues of PLWH in their clinics.<sup>[19]</sup>

***Consequences of stigma***

Possible consequences of stigma can include: the undermining of care and treatment (e.g. delaying medical appointments), limited opportunities for integration into society, and economic independence.<sup>[30]</sup> Furthermore, a consequence of stigma might be that PLWH refrain from certain types of jobs (not specified).<sup>[37]</sup>

## Discussion

Due to improved life expectancy, work participation and working conditions, including disclosure of HIV status and stigma, have become important issues in the daily lives of PLWH. This study is the first scoping review to examine the work-related issues disclosure and stigma.

This study shows that the level of disclosure at work is low, ranging from 22-50%. The main reason for non-disclosure is the fear of stigma. However, the level of reported stigma is low (6-11%). Since the HIV virus can be successfully suppressed by medication, the need to disclose this status has become less urgent and does not need to influence the ability to work. Reasons for disclosure include mainly personal reasons, such as the desire to be honest or to be accepted, or reasons related to the extent to which HIV influences the ability to work.

Compared to work-related disclosure in other chronic diseases the level of disclosure at work of PLWH is average. For example, people with diabetes are more likely to disclose their health status at work, i.e. 84%, compared with about 50% among breast cancer survivors, and only 37% disclosure among people with a mental illness.<sup>[38, 39]</sup> The level of disclosure of PLWH among other persons (such as spouses and friends) was higher, ranging from 60-96%.<sup>[8]</sup>

The increased level of knowledge among the general population is one of the reasons why, at least in these settings, discussing seropositivity is easier compared to a decade ago.<sup>[6]</sup> Although not yet investigated, increasing knowledge on HIV in the context of work might also encourage disclosure.

Determinants of disclosure at work which were only slightly touched upon by the studies in the present review, are ethnicity and sexual preference. However, it is important to take into account that, in other settings, immigrant PLWH are probably less likely to disclose their HIV status due to the perception of HIV/AIDS in their country of origin, and the fear of rejection.<sup>[40]</sup> This also applies to men who have sex with men, who may suffer from homonegativity, i.e. the stigma associated with homosexuality.<sup>[41]</sup> PLWH often experience multiple stigmatized identities which influence their decisions about disclosing their HIV status in various settings, including work. In the counseling of PLWH it is important to take these multiple stigmatized identities into account.

Stigma, as a social construct, is not rigid but varies between different cultures, groups and organizations. Stigma can be divided into subtypes, such as enacted stigma, perceived stigma, and internalized stigma.<sup>[42]</sup> Although the studies included in this review describe enacted, perceived and internalized stigma, the interactions between these forms of stigma remain unclear, as does the distinction between groups and organizations. It can be assumed that there is a difference in the understanding of the construct of stigma across studies.

The included studies did not clarify the relation between (fear of) stigma and subgroups of PLWH based on health status or psychological consequences. The prevalence of anxiety and depression among PLWH is higher than that of the general population.<sup>[4]</sup> HIV-related stigma can have a negative impact on health aspects and the wellbeing of PLWH.<sup>[43]</sup> It is recommended to further examine the role of stigma on health and wellbeing at work in order to provide appropriate counseling.

This review found no evidence for the constructs which play a role in the disclosure process in relation to work. The Disclosure Processes Model describes different constructs that play a role in the

disclosure process, such as antecedent goals (approach or avoidance), the disclosure event itself, mediating processes (i.e. inhibition or alleviation), and outcomes such as social and physical wellbeing. [44] Further insight into the complexity of disclosure in relation to work will help PLWH to develop strategies to cope with this complex issue.

The available literature was heterogeneous and in most studies the topics of our interest were secondary outcomes and provided only basic insights. A limitation of this scoping review is the restriction to Western countries. Studies from other geographical regions might have added information which might be relevant for Western countries. Despite these limitations, the data synthesized in this study provide a broader understanding of work-related stigma and disclosure.

## Conclusion

This review provides a unique overview of the available research on work-related disclosure and stigma, which is indispensable for understanding and improving the position of PLWH in the labor market. This study also shows that further investigation of the underlying mechanisms of work-related stigma and disclosure is needed because research in this field is still in its early stages.

### Practice Implications

Disclosure and stigma are some of the main work-related issues for PLWH. In the counseling of PLWH it is important that healthcare providers are aware of the dilemma about disclosure at work and that they support PLWH to make a well-considered decision. In this context it should be considered that, although HIV is a chronic disease, its social acceptance is not yet comparable to other chronic diseases because it is predominantly sexually transmitted. Healthcare providers should also take into account the possible differences between various subgroups, such as immigrants or homosexual PLWH, who may experience multiple stigmatized identities.

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### Conflicts of interest

The manuscript has been seen and approved by all authors and all authors declare no conflicts of interest.

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## Appendix 1: Search strategy

(“Acquired Immunodeficiency Syndrome”[Mesh] OR “HIV”[Mesh] OR “HIV Infections”[Mesh] OR acquired immune deficiency syndrome\*[tiab] OR aids[tiab] OR htlv-iii[tiab] OR human immunodeficiency virus\*[tiab] OR human t cell lymphotropic virus type iii[tiab] OR lav-htlv-iii[tiab] OR lymphadenopathy-associated virus\*[tiab] OR hiv infection\*[tiab] OR htlv-iii-lav infection\*[tiab] OR hiv seropositiv\*[tiab] OR anti-hiv positiv\*[tiab] OR seropositiv\*[tiab] OR hiv-seroconverts\*[tiab] OR aids seroconverts\*[tiab] OR hiv antibody positiv\*[tiab]) AND (“Employment”[Mesh] OR “Job Application”[Mesh] OR “Rehabilitation, Vocational”[Mesh] OR “Unemployment”[Mesh] OR “Vocational Guidance”[Mesh] OR “Sick Leave”[Mesh] OR “Absenteeism”[Mesh] OR employment[tiab] OR underemployment[tiab] OR occupational status\*[tiab]) AND (prejudice\*[tiab] OR stigma\*[tiab] OR social discrimination[tiab] OR sexism[tiab] OR segregation[tiab] OR disclosure[tiab] OR “Prejudice”[Mesh] OR “Truth Disclosure”[Mesh])

AND

(“1996/01/01”[edat] : “2016/02/28”[edat]) OR (“1996/01/01”[mhda] : “2016/02/28”[mhda])



# LIVING WITH HIV

Implications for work participation

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## Chapter 6

# DETERMINANTS OF EMPLOYMENT IN PEOPLE LIVING WITH HIV IN THE NETHERLANDS



### Authors

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### Abstract

**OBJECTIVES** Since HIV has become a manageable chronic disease, employment is of increasing importance for people living with HIV (PLWH). This study aimed to investigate the level of work participation among PLWH in the Netherlands, and the associated determinants of employment.

**METHODS** For this study the baseline measurements of a longitudinal cohort study with a 2-year follow-up, the TREVI project, were used. The TREVI project aims to study cognitive function disorders among PLWH in relation to their employment, productivity, and social functioning.

From December 2012 until December 2013, data on cognitive functioning, measured by the HIV Dementia Scale, and medical data derived from patient records were collected. Employment status and possible determinants of employment were assessed by a digital survey. Chi square analysis and multivariate logistic regression analysis were conducted in order to investigate the level of employment and associated determinants of employment.

**RESULTS** This cross-sectional study revealed significant differences in the level of employment compared with Dutch reference data: i.e. in the age group 40-54 years PLWH had a significantly lower employment rate than the general Dutch population. Multivariate analysis showed that employment was negatively associated with a lower or higher age (reference: 40-54 years), a longer period since diagnosis, problems with physical functioning, and a higher score on the HADS Depression. Having paid work at diagnosis was positively associated with employment.

**CONCLUSION** PLWH, particularly in the age of 40-54, in the Netherlands have a significant lower level of employment compared to the general population. Counseling should address reduced psychological and physical functioning in order to improve the position of PLWH on the labor market.

### Key Words

*Cohort study*

*Employment*

*HIV*

*Vocational guidance*

## Introduction

The life expectancy of people living with HIV (PLWH) has increased substantially since the introduction of combination antiretroviral therapy. In high-income countries, such as the Netherlands, HIV can nowadays be seen as a chronic disease. With reduced mortality and longer survival, the quality of life of PLWH has become increasingly important.<sup>[1]</sup> Participating in society and having a job is an important component of the quality of life and has proven beneficial for PLWH because it helps to structure life, leads to social contacts, provides identity and status, and helps to set targets and obtain resources.<sup>[2]</sup> Moreover, employment status is reported to be strongly related to better physical/mental health and quality of life among PLWH.<sup>[3]</sup>

Employment is negatively affected by chronic diseases.<sup>[4, 5]</sup> Previous research on employment showed that the level of unemployment among PLWH is substantially higher than in the overall labor force with comparable demographic characteristics. PLWH contemplate returning to work but are still unable to be gainfully employed due to perceived barriers such as loss of income disability benefits.<sup>[6-9]</sup> Therefore, the impact of HIV on work participation appears to be substantial. In addition, PLWH often experience stigma and discrimination at work<sup>[10-12]</sup>, or when returning to work after a period of work disability.

Moreover, various disease-related factors may influence a patient's employability. First, neurocognitive functioning may play a significant role in occupational success and maintenance. For example, van Gorp et al. showed that an index of learning and memory stood out as a robust predictor of finding employment.<sup>[13]</sup> Secondly, another symptom of HIV affecting a patient's ability to work is fatigue, which has a prevalence of about 20-60% in this patient population. Finally, depression and other psychosocial issues among PLWH are known to influence their ability to work.<sup>[1, 3, 10]</sup>

In 2012, a multidisciplinary guideline on 'HIV and Work' was developed in the Netherlands.<sup>[11, 14]</sup> In this context, background studies (including a literature review, a qualitative study on work experiences of PLWH, and an expert panel) acknowledged the topicality and relevance of the above-mentioned determinants, and also highlighted the lack of studies addressing vocational outcomes among PLWH.

Therefore, this study investigates the level of work participation and related determinants among PLWH in the Netherlands. Apart from aiming to confirm determinants already described, we also explore the relevance of additional determinants emerging from the development of related guidelines in the Netherlands.

## Methods

### **Study design**

For this study the baseline measurements of a longitudinal cohort study with a 2-year follow-up, the TREVI project, were used. The TREVI project aims to study cognitive function disorders among PLWH in relation to their employment, productivity, and social functioning.

### **Study population**

The population for the present study consists of PLWH attending the outpatient clinic of the Erasmus Medical Center (EMC; Rotterdam, the Netherlands). Patients were eligible for enrolment if they spoke adequate Dutch. Patients were excluded if they had a current opportunistic central nervous system infection, had current schizophrenia, current severe affective disorder believed to account for the subject's cognitive impairment, or a current neurological disorder such as epilepsy or multiple sclerosis.

### **Procedures**

From December 2012 until December 2013, all eligible patients visiting the outpatient clinic of EMC were invited to participate in the TREVI project by their HIV physician or HIV nurse. If they were interested, patients underwent cognitive screening by a trained research assistant, using the International HIV Dementia Scale.<sup>[15]</sup> This is a standardized and internationally validated cognitive screening tool, which takes  $\pm$  2-3 min to complete. Patients with a score of 10 points (out of 12) or less, were considered for further evaluation of cognitive functioning. In addition, they received an informed consent document (with a random document number), information letter, and either an email with a web link to the questionnaire or a hardcopy questionnaire.

After the informed consent document was returned, we linked the document number to patient data, using a key that was in the possession of the principle investigator only. The questionnaire could be completed anonymously using a secured online survey system. Only the researchers had access to the survey responses. In case of non-response, a reminder was sent after 2 and 4 weeks.

The study was reviewed by the Medical Ethics Committee of the EMC and approved as not falling under the scope of the Medical Research Involving Human Subjects Act (WMO).

### **Outcome measures**

Employment status was assessed by asking participants if they had a paid job at the time of completing the questionnaire.

### ***Determinants of employment***

Possible determinants for employment status were derived from a systematic literature review, a qualitative study<sup>[11]</sup> and recommendations from the expert panel that was involved in developing the multidisciplinary guideline on 'HIV and Work'.<sup>[14]</sup> The following determinants were included in the questionnaire.

***Background characteristics.***

Gender, age, educational level, presence of children, sexual orientation, and marital status were assessed. Education level referred to the highest level of education completed and was divided into three categories: low (no, primary or lower secondary, and lower vocational education), middle (intermediate secondary and intermediate vocational education), and high (higher vocational education and university). Marital status was dichotomized as: married/cohabiting versus single (including divorced or widowed).

***Medical status***

Medical data (i.e., CD-4 count, CD-4 nadir, and viral load) were derived from patient records. Viral load measurements were divided into two groups: < 200 co/ml and  $\geq$  200 co/ml.

***Work history***

All respondents were asked about their work history over the past 12 months, e.g. if they had applied for another job. Furthermore, they were asked to indicate whether they had stopped or changed work since their HIV diagnosis.

***Psychological functioning***

Psychological functioning was measured with the anxiety and depression dimensions of the Hospital Anxiety and Depression Scale (HADS).<sup>[16]</sup> The HADS contains 7 items relating to anxiety and 7 relating to depression. Items are answered on a 4-point Likert scale, resulting in a score of 0-21 on each construct (depression or anxiety). A score of  $\geq$  8 points indicates a psychiatric problem. At the intake of participants for the present study (at the outpatient clinic), scores on the International HIV Dementia Scale<sup>[15]</sup> were recorded.

***General health and daily functioning***

Health-related quality of life (HRQL) was measured with the MOS-HIV, a HIV-specific instrument consisting of 35 items addressing 10 dimensions of health (overall health, physical functioning, social and role functioning, cognitive functioning, pain, mental health, energy, distress, and quality of life).<sup>[17]</sup> The subscales of the MOS-HIV were scored as summated rating scales on a 0-100 scale, with higher scores indicate better HRQL. From these 10 subscales, two summary scores were created: the Physical Health Summary score (PHS) and a Mental Health Summary score (MHS).<sup>[18]</sup>

***Disclosure***

The level of disclosure was measured by asking who had been informed about the HIV infection. This question was asked for 13 different situations (e.g. sexual partner, close family, friends, neighbors, colleagues, in contacts with the healthcare sector, etc.). The answer options varied from (1) not disclosed at all to (6) full disclosure. The 13 different situations were reclassified into 4 groups: 1) sexual partner and close family, 2) social network, 3) work, and 4) contacts with financial and health sector. Also, a total disclosure score was calculated by summarizing the scores on all 13 different situations.

The mean score for every group, and for the total sample was calculated, ranging from 1-6.

### ***Stigma***

Stigma was measured by asking about experienced stigma in the same situations as described for disclosure. The answer options were: never, rarely, sometimes, and often. An overall score for the experienced stigma in various situations was calculated by summarizing the scores on all these items, resulting in a mean score ranging from 1 (never) to 4 (often). Stigma was also measured by a selection of four items from the Berger Stigma Scale<sup>[19]</sup>, of which a mean score was calculated ranging from 1 (completely disagree) to 5 (completely agree).

### ***Lifestyle***

Smoking, drinking, exercising and eating behavior were assessed by several questions, as in Rappange et al.<sup>[20]</sup> Smoking was measured by asking 'Do you smoke?' (answer options: 'yes', 'no, not anymore', 'no, never smoked'). Drinking behavior was measured by asking about the number of alcoholic consumptions per week. Participants were categorized as 'no', 'moderate' or 'excessive drinker', based on Dutch guidelines.<sup>[21]</sup> Exercising was measured by the number of days per week with at least 30 min of exercise/day.<sup>[22]</sup> Eating behavior was measured by the number of days a week that balanced meals (a varied diet, rich in vegetables, fruit and whole-grain cereal products) were eaten.<sup>[21]</sup>

### ***Volunteer work and informal care***

Respondents were asked to indicate whether they performed volunteer work or informal care at the time of the survey.

### **Statistical analyses**

Statistical analyses were restricted to the participants who gave informed consent and had completed the full questionnaire. For all statistical analyses SPSS software (IBM Corp, Released 2014, IBM SPSS Statistics for Windows, Version 22.0. Armonk, NY) was used. Descriptive statistics were used to describe the characteristics of the study population. These descriptive data were analyzed for between-group differences with bivariate analyses (ANOVA) for numeric and continuous variables and Chi-square analyses for ordinal variables. A p-value < 0.05 was regarded as statistically significant. Chi-square statistics were applied to compare the level of work participation among the participants of this study with the general Dutch population.<sup>[23]</sup> These analyses were conducted for various subgroups (gender, age, educational level). A p-value < 0.05 was regarded as statistically significant. Logistic regression analyses were used to explore associations, expressed as odds ratios (OR) with corresponding 95% confidence intervals (CI), between the dependent variable employment status (having paid work for at least 1 h/week) and the possible determinants. Bivariate logistic regression was used to determine the single effects of all determinants of interest. Variables with a p-value < 0.1 were included in the multivariate analysis. Multicollinearity between constructs was measured by assessing the Variance Inflation Factor. A backward logistic regression technique was performed to determine the multivariate model with the best overall fit. In this analysis, independent variables

with a p-value < 0.05 were retained in the final model. Variables were considered in blocks of related determinants (i.e., background characteristics, medical status, work history, cognitive functioning, general health, disclosure and stigma, lifestyle, volunteer work and informal care). The order of the blocks was determined based on the expected influence of the determinants, as observed in previous research. ORs, the 95% CI, and the change in the percentage of explained variance (incremental R square), are reported as results of the multivariate logistic regression analysis.

Results

Baseline characteristics

Of the estimated eligible patients (n=600) visiting the outpatient clinic of EMC<sup>[24]</sup>, 400 were interested to participate in this study. Of these, 315 (79%) completed the survey. Informed consent was obtained from all individual participants included in the study. Table 1 presents the baseline characteristics of the study sample. The group consisted of 87% men/13% women, with a mean age of 48 years. Overall, the participants had a relatively high education level.

**Table 1** *Baseline characteristics of participants and differences between employed and unemployed participants at the time of enrolment in the cohort.*

<i>Variable</i>	<i>Total</i>				<i>Employed</i>				<i>Not Employed</i>			
	<i>N</i>	<i>%</i>	<i>Mean</i>	<i>SD</i>	<i>N</i>	<i>%</i>	<i>Mean</i>	<i>SD</i>	<i>N</i>	<i>%</i>	<i>Mean</i>	<i>SD</i>
<i>Total</i>	315				206	65			109	35		
Gender												
Female	41	13			23	11			18	17		
Male	274	87			183	89			91	83		
Age*			48.1	10.6			45.7	8.9			52.6	12.1
Age group in years												
20-39*	63	20			46	22			17	17		
40-54*	168	53			126	61			42	42		
55-75*	84	27			34	17			50	50		
Marital status, % (n)												
Married or living together*	143	45			106	52			37	34		
Single, divorced or widowed*	172	55			100	48			72	65		
Has children												
No*	249	79			170	83			79	73		
Yes*	66	21			36	17			30	27		

Variable	Total				Employed				Not Employed			
	N	%	Mean	SD	N	%	Mean	SD	N	%	Mean	SD
Total	315				206	65			109	35		
Educational level												
Low*	73	23			38	18			35	32		
Middle*	106	34			72	35			34	31		
High*	36	43			96	47			40	37		
Sexual orientation												
Mainly attracted to men	268	85			179	87			89	82		
Both men and women	13	4			7	3			6	6		
Mainly attracted to women	33	11			19	9			14	13		
Medical status												
Months since diagnosis*			94.7	79.8			81.9	70.8			119.1	89.9
CD4 Nadir			260	173			268	171			245	178
CD-4			641	329			630	270			662	420
Viral load												
<200 co/ml	219	70			143	70			76	70		
≥200 co/ml	94	30			62	30			32	30		
Work history												
Work status at diagnosis*												
No paid work	63	20			17	8			46	42		
Paid work	251	80			188	92			63	58		
Change of work status since diagnosis* N=251												
No	140	44			113	60			27	44		
Yes, I quit working	23	7			3	2			20	32		
Yes, I reduced my hours	18	6			12	6			6	10		
Yes, I changed my hours	4	1			4	2			0	0		
Yes, I have another function	15	5			15	8			0	0		
Yes, I have another job	26	8			24	13			2	3		
Yes, other	24	8			17	9			7	11		
Change of work status caused by HIV* N=112												
No	64	20			57	75			7	19		
Yes, because of physical problems caused by HIV	28	9			10	13			18	50		
Yes, because of psychological problems caused by HIV	6	2			3	4			3	8		



<i>Variable</i>	<i>Total</i>				<i>Employed</i>				<i>Not Employed</i>			
	<i>N</i>	<i>%</i>	<i>Mean</i>	<i>SD</i>	<i>N</i>	<i>%</i>	<i>Mean</i>	<i>SD</i>	<i>N</i>	<i>%</i>	<i>Mean</i>	<i>SD</i>
<i>Total</i>	315				206	65			109	35		
Yes, because of stigma/discrimination at work caused by HIV	3	1			0	0			3	8		
Yes, other	1	2			6	8			5	14		
<i>General Health and daily functioning</i>												
MOS-HIV:	54.5	7.9			56.5	5.8			50.6	7.4		
Physical Health Summary Score*												
MOSHIV:	51.5	8.8			53.8	7.6			47.1	9.4		
Mental Health Summary Score*												
<i>Psychological factors</i>												
HADS: Anxiety												
No*	238	76			175	85			63	58		
Possible*	30	9			18	9			12	11		
Probably*	47	15			13	6			34	31		
HADS Anxiety			5.0	4.0			4.0	3.3			6.9	4.6
HADS: Depression												
No*	255	81			184	89			71	65		
Possible*	28	9			13	6			15	15		
Probably*	32	10			9	4			23	21		
HADS Depression*			3.9	4.2			2.7	3.4			6.0	4.6
International HIV Dementia Scale*			10.8	1.3			11.0	1.2			10.4	1.5
<i>Disclosure</i>												
Total*			2.8	1.2			2.6	1.1			3.1	1.3
Sexual partner and close family			4.4	1.6			4.3	1.6			4.7	1.5
Social Network*			2.3	1.3			2.1	1.1			2.7	1.5
Work			1.9	1.6			1.8	1.6			1.9	1.6
Financial and health sector			3.8	1.8			3.6	1.8			4.0	1.7
<i>Stigma</i>												
Experienced general*			1.4	0.6			1.3	0.5			1.6	.7
Experienced items Berger Scale*			2.2	1.1			1.9	1.0			2.6	1.2

Variable	Total		Employed				Not Employed			
	N	%	Mean	SD	N	%	Mean	SD	N	%
Total	315				206	65			109	35
Life style										
Smoking, % (n)										
No	213	32			150	73			63	58
Yes	102	68			56	27			46	42
Drinking										
No*	82	26			49	24			33	31
Moderate*	207	66			145	71			62	58
Excessive	21	7			9	4			12	11
Eating healthy			6.6	1.4			6.7	1.6		
Exercise			5.2	2.3			5.1	2.3		
Social security										
Receiving a benefit N=294										
No*	217	69			193	95			24	26
Yes*	77	25			9	5			68	74
Searching for another job n=296										
Searching for another job in the past 12 months										
No	222	71			158	78			64	70
Yes	73	23			45	22			28	30
Informal care										
Informal care family or roommate*										
No	278	88			187	91			91	84
Yes	36	12			18	9			18	16
Informal care other people*										
No	300	95			200	98			100	92
Yes	14	5			5	2			9	8
Volunteering*										
No	266	85			189	92			77	71
Yes	48	15			16	8			32	29

\*p<0.05, n=number of participants, SD=standard deviation,  
Employed was defined as working ≥ 1 hour a week.

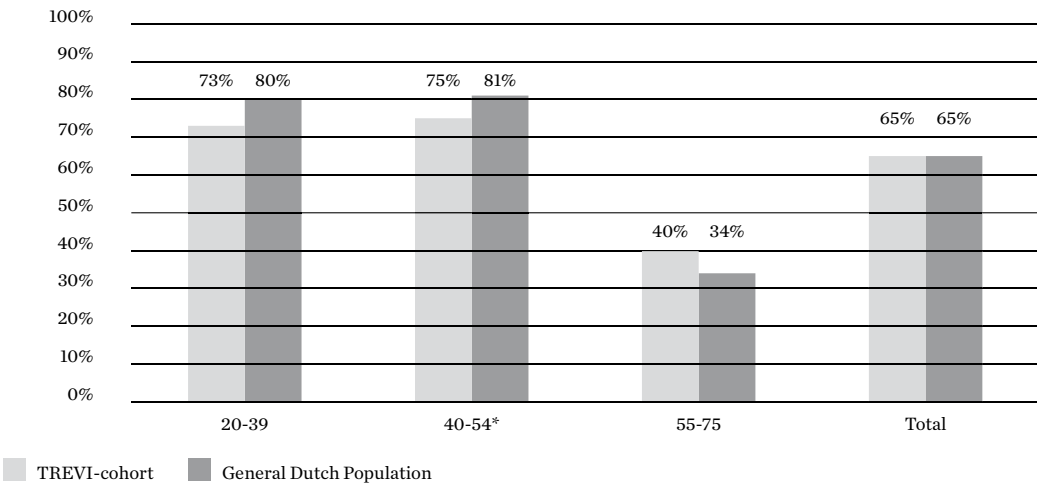
Employed versus unemployed participants

Almost two out of three participants (65.3%) had a paid job at the time of the survey. Compared with participants without employment, the 207 employed participants had a higher educational level (47% versus 37%). At the time of the diagnosis, 80% of the participants had a paid job. The work situation of 15% of the participants had changed because of HIV (e.g. reducing hours, changing hours, and another function). Overall, the scores on medical data were comparable between both groups, although those without employment had been diagnosed with HIV for a longer period of time (119 months versus 82 months).

Level of employment compared to the general Dutch population

The employment level for the total group of men and women was not significantly lower than that of the general Dutch population. Figure 1 shows the level of employment for the three age groups in the TREVI cohort compared to the general Dutch population. The level of employment for the group aged 40-54 years was significantly lower than that in the general Dutch population (75% versus 81%).

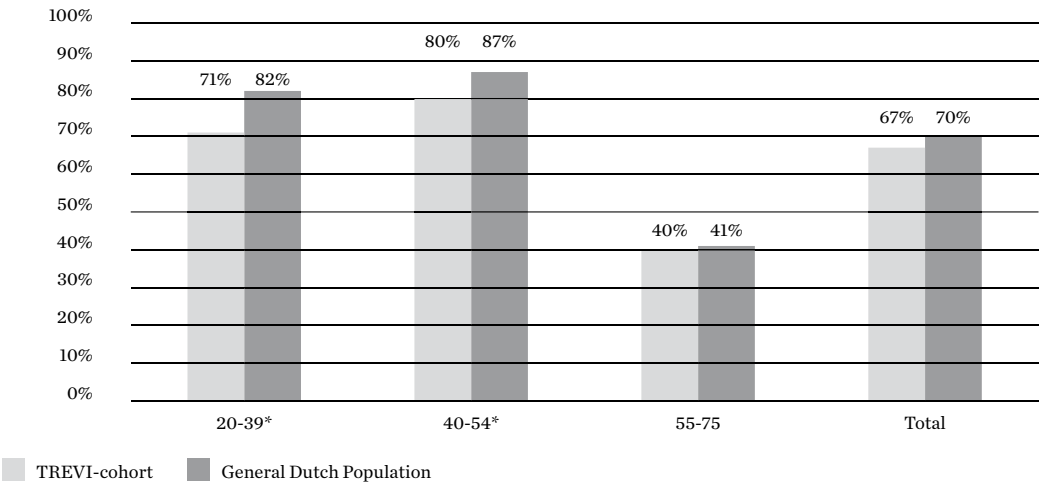
Figure 1 Level of employment in the TREVI cohort vs. the general Dutch population, by age group (in years)



\*p<0.05

Among men, the level of employment was significantly lower in the age groups 20-39 years (71% versus 82%) and 40-54 years (80% versus 87%) (Figure 2). No significant differences in employment were found between the TREVI cohort and the general Dutch population based on the level of education.

**Figure 2** *Level of employment among men, by age group (in years)*



\*p<0.05

The employed participants had a lower score on the HADS Anxiety scale, 6% was indicated as probably having an anxiety disorder (versus 31% of the unemployed participants). In addition, their score on the HADS Depression scale was significantly lower, 4% was indicated as probably having a depression (versus 21% of unemployed participants). Participants with employment reported a significantly lower level of experienced stigma on the items of the Berger Stigma Scale than unemployed participants (1.9 versus 2.6 on a scale from 1-5).

**Characteristics related to employment status**

*Table 2 presents the results of the bivariate analysis.*

**Table 2 Bivariate logistic regression models for characteristics associated with employment (n=315)**

Characteristics	OR	95% C.I.
<i>Background</i>		
Male (ref. female)	1.57	.81 - 3.06
Age	.94*	.91 - .96
Age in years (ref. 40-54 years)		
20-39	.90	.47 - 1.74
55+	.23*	.13 - .40
<i>Marital status</i>		
Married or living together (ref. Single, divorced or widowed)	2.06*	1.27 - 3.34
Has children (ref. no)	.56*	.32 - .97
<i>Educational level (ref. low)</i>		
Middle	1.95*	1.01 - 3.61
High	2.21*	1.23 - 3.98
<i>Sexual orientation (ref. mainly men)</i>		
Both men and women	.58	.19 - 1.78
Mainly women	.68	.32 - 1.41
<i>Medical status</i>		
Months since diagnosis	.99*	.99 - 1.00
CD-4	1.33	.380 - 1.51
CD4 Nadir	1.36	.21 - 8.72
Viral load (ref. <200 co/ml)	1.03	.62 - 1.71
<i>Work history</i>		
Working at diagnosis (ref. not working)	8.03*	4.32 - 15.09
<i>General Health</i>		
MOS-HIV: Physical Health Summary Score	1.10*	1.05 - 1.15
MOSHIV: Mental Health Summary Score	1.05*	1.01 - 1.09
<i>Psychological factors</i>		
HADS: Anxiety	.93	.85 - 1.02
HADS: Depression	.87*	.80 - .95
International HIV Dementia Scale	1.40*	1.15 - 1.70

## CHAPTER 6

Determinants of employment in people living with HIV in the Netherlands

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<i>Disclosure</i>		
Total	.11*	.01 - 1.15
Work	1.77*	.97 - 3.22
<i>Stigma</i>		
Experienced general	.66	.38 - 1.14
Experienced items Berger Stigma Scale	.70*	.52 - .95
<i>Life style</i>		
Smoking (ref. non smoking)		
Yes	.35*	.20 - .63
Not anymore	.46*	.25 - .84
Drinking (ref. yes)		
No	.72	.43 - 1.22
Eating healthy	.96	.81 - 1.14
Exercise	.95	.86 - 1.06
<i>Informal care</i>		
Conducting informal care family or roommate (ref. no)	.49*	.24 - .98
Conducting informal care other people (ref. no)	.28*	.09 - .85
<i>Volunteering</i>		
Volunteering (ref. no)	.20*	.11 - .39

OR=odds ratio, \*p<0.1, CI=95% confidence interval

The following characteristics were significantly associated with employment: age, marital status, having children, educational level, months since diagnosis, work status at diagnosis, score on the MOS HIV Physical and Mental Health Summary, HADS Depression, International HIV Dementia Scale, total level of disclosure, disclosure at work, experienced stigma (using the Berger stigma scale), smoking, conducting informal care, and volunteering. For example, lower employment status was observed in PLWH who had a higher score on the HADS Depression scales (OR 0.87, 95% CI 0.80-0.95) and a lower score on the HIV Dementia Scale (OR 1.40, 95% CI 1.15-1.70). Participants who had a paid job at the time of diagnosis (OR 8.03, 95% CI 4.32-15.09) were significantly more likely to have a paid job at the time of the survey.

Table 3 presents the results of the multivariate model of determinants of employment among PLWH.

Table 3 Multiple logistic regression analysis of determinants of employment in the study population with HIV.

	Step 1		Step 2		Step 3		Step 4		Step 5		Step 8	
	OR	95% C.I.	OR	95% C.I.	OR	95% C.I.	OR	95% C.I.	OR	95% C.I.	OR	95% C.I.
<i>Block 1 Background characteristics</i>												
Age (ref. 40-54)												
20-39	.68	(.42-1.75)	.67	(.32-1.41)	.59	(.27-1.33)	.50	(.22-1.14)	.38*	(.15-.96)	.37*	(.14-.93)
55+	.28*	(.14-.53)	.29*	(.15-.56)	.30*	(.15-.62)	.35*	(.17-.74)	.21*	(.09-.50)	.22*	(.09-.51)
<i>Marital Status (ref. Single, divorced or widowed)</i>												
Married or living together	2.28*	(1.29-4.04)	2.26*	(1.22-4.20)	2.26*	(1.22-4.20)	1.99*	(1.10-3.76)	1.58	(.79-3.18)	1.62	(.81-3.27)
Months since diagnosis	.	.	.99*	(.99-.99)	.99*	(.99-1.00)	.99*	(.99-1.00)	.99*	(.99-1.00)	.99*	(.99-1.00)
<i>Block 3 Work history</i>												
Working at diagnosis (ref. not working)	.	.	.	.	8.58*	(3.92-18.78)	9.04*	(4.04-20.24)	8.07*	(3.39- 19.23)	7.54*	(3.13-18.20)
<i>Block 4 Cognitive functioning</i>												
International HIV Dementia Scale	.	.	.	.	.	.	1.43*	(1.13-1.82)	1.25	(.96-1.62)	1.25	(.96-1.63)
<i>Block 5 General Health (physical and psychological functioning)</i>												
MOS-HIV: Physical Health Summary Score	.	.	.	.	.	.	.	.	1.09*	(1.03-1.15)	1.08*	(1.02-1.05)
HADS: Depression	.	.	.	.	.	.	.	.	.89*	(.81-.96)	.87*	(.80-.95)

	Step 1		Step 2		Step 3		Step 4		Step 5		Step 8	
	OR	95% C.I.	OR	95% C.I.	OR	95% C.I.	OR	95% C.I.	OR	95% C.I.	OR	95% C.I.
<i>Block 7 Informal care and volunteering</i>												
Volunteering (ref. no)	.	.	.	.	.	.	.	.	.	.	.45	(.17-.113)
Total R square	.12	.	.15	.	.29	.	.33	.	.46	.	.47	.
Incremental R square	.	.	0.03	.	.14	.	.04	.	.13	.	.01	.

\*p<0.05  
Additional information about the steps: Step 1: Background characteristics: educational level and having children not included / Step 2: - / Step 3: - / Step 4: - / Step 5: General Health: MOS HIV MHS not included / Step 6: Did not add to the R square. In this step: Disclosure work, disclosure total, Experienced Stigma Berger Scale not included / Step 7: Did not add to the R square. In this step: Lifestyle: smoking not included / Step 8: Informal care and volunteering not included



All variables included in the model together explained 47% of the variance. Work status at diagnosis had the greatest influence on the R-square. In the final model, the variables age, months since diagnosis, score on the MOS HIV Physical Health Summary, work status at diagnosis, and the score on the HADS Depression were significant characteristics related to employment.

## Discussion

This study contributes to a small but growing body of literature on PLWH and employment. The results show that PLWH in the Netherlands clearly have problems regarding their work participation and work situation.

In this study, at first glance the overall level of employment among PLWH in the Netherlands seems similar to the general Dutch population. However, on closer analysis, among an important part of the labor force (the age group 40-54 years), the level of employment of the TREVI cohort was significantly lower compared to the general Dutch population (relative reduction of 6%). Especially men in this age group (but also in the age group 20-39 years) had a significantly lower level of work participation (in the age group 20-39 years a relative reduction of 11%, and in the age group 40-54 years of 7%). Due to a lack of power it was not possible to provide more insight into the employment of women.

In contrast to earlier reports on PLWH<sup>[6, 8, 25]</sup>, the overall level of employment in the Dutch sample was relatively high (65% in this study versus 40-55% in other studies); however, in those latter studies no distinction was made between subgroups. Compared to a previous Dutch study<sup>[26]</sup> the employment level in the TREVI cohort was low, especially in the youngest group (20-40 years; 73% versus 86%) and in the oldest group (55-75 years; 40% versus 48%). This may be related to the composition of the sample (e.g. distribution in education level) or to the status of the labor market/ economic situation, which may have been less favorable at the time of the survey.

Subsequently, we examined factors that could explain differences in employment among PLWH. It was found that age, months since diagnosis, work status at diagnosis, the MOS HIV Physical Health Summary score, and the HADS Depression score were factors significantly related to employment. In the present study, being younger or older than the reference group was negatively related to employment. Previous studies also described that older people have less chance of getting a paid job<sup>[6-9, 27-33]</sup>, which does not differ from the general population. The lower employment rate in our younger age group might be explained by the fact that younger PLWH do not yet have a stable working position and may still experience many changes in their personal life. There are indications that fluctuations in the disease and uncertainty about the prognosis are negatively associated with employment.<sup>[6, 9, 34]</sup> Therefore, being HIV positive makes it harder to find and keep a paid job and start a career. In our multivariate analysis a lower MOS HIV Physical Health Summary score and a higher HADS Depression score were significantly associated with unemployment. The role of the MOS HIV Physical Health Summary score confirms results from other studies, that physical limitations in PLWH are

associated with decreased employment.<sup>[2, 6, 8-10, 27, 29, 33, 35, 36]</sup> With regard to depression the evidence remains contradictory; for example, Rabkin et al., Ezzy et al. and the present study support a negative association, whereas Lem et al. do not.<sup>[8, 33, 37]</sup>

The relation between work history and actual level of employment among PLWH is not extensively studied. Only one qualitative study concluded that a gap in the resume of PLWH was a barrier for return to work.<sup>[30]</sup> In our study, having a paid job at the time of diagnosis was the strongest factor related to employment at the time of the survey. However, this result should be interpreted with caution because there could be other reasons why participants had no job at the time of diagnosis and of the survey. Nevertheless, because being employed at the time of diagnosis is an advantage for staying employed, it is important to make every effort to maintain work.

The results of our multivariate analysis do not confirm the role of some determinants described in other studies, such as impaired cognitive functioning, stigma and disclosure. Impaired cognitive functioning has been associated with problems at work and as a barrier for return to work.<sup>[2, 9, 33, 38]</sup>

In our study a higher score on the International HIV Dementia Scale was not significantly related to unemployment. This may be explained by a limited variation in cognitive impairment in our HIV population. In future studies, comparison with the general population is also needed. In order to further investigate the relation between cognitive functioning and employment among PLWH, we will investigate the association between the results of neuropsychological evaluation and employment. Stigma and disclosure are reported to be work-related issues affecting employment among PLWH.<sup>[2, 6, 7, 10, 39-42]</sup> However, in our study neither stigma nor disclosure remained in our multivariate model; additional studies are required for further insight into these determinants.

The present study has some limitations. First, since our data were cross-sectional, the observed relations cannot be interpreted as causal. However, many of our results are in line with other studies, indicating that these associations should be further explored in longitudinal research.

Second, some selection bias may have occurred as our sample included only Dutch-speaking patients from one outpatient clinic. For example, non-Dutch speaking migrants were not included in the study and this subgroup of the population may experience additional or different problems related to employment, such as stigma because of their ethnicity. On the other hand, this selection can also be regarded as a strength of our study because it avoids other influencing factors, such as language difficulties. The present study had insufficient power to draw conclusions regarding female PLWH, who might have different experiences related to the keeping or finding a paid job. Therefore, because our results cannot be generalized to all PLWH in the Netherlands, additional studies are needed on HIV and work among other ethnic groups and women with HIV. Furthermore, because the majority of our participants were homosexual, they may have to deal with a double stigma related to their HIV status and their homosexuality.

In many countries loss of social services is an issue among PLWH.<sup>[2, 10, 30, 35, 41]</sup> In the Netherlands this is not necessary because in case of unemployment PLWH can apply for an unemployment benefit. However, in future research in other countries this possible determinant of employment, depending

on the local insurance system, might be taken to account.

Furthermore, data on non-participation and non-response were not registered. Also, as employment was the main topic of this study, it is possible that mainly people with work (or interested in work) responded to the survey. If we have missed those individuals who function less well in the work situation, this may imply that the problem of employment among PLWH has been underestimated.

Finally, most data in this study were self-reported and (even though participation was anonymous), the responses may be subject to social desirability and/or recall bias.

In conclusion, by providing insight into the employment level and several factors associated with employment, this study highlights possible issues to be addressed in the vocational guidance of PLWH, and emphasizes the importance of surveillance of the work status and work-related problems of PLWH. Such information is important to provide proper counseling and may also be used for policy development, in work organizations, and even at the national level. Finally, the study underlines the need for longitudinal research to clarify the causality in the relationship between determinants and employment.

### **Compliance with Ethical Standards:**

**FUNDING:** This study was supported with an educational grant from Janssen Pharmaceutical Companies.

**CONFLICT OF INTEREST:** The authors declare that they have no conflict of interest.

**ETHICAL APPROVAL:** All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

**INFORMED CONSENT:** Informed consent was obtained from all individual participants included in the study.

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# LIVING WITH HIV

Implications for work participation

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## Chapter 7

# **ARE PEOPLE LIVING WITH HIV LESS PRODUCTIVE AT WORK?**



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### Abstract

**OBJECTIVE** Health problems may cause decreased productivity among working people. It is unclear if this also applies for people living with HIV (PLWH). This study investigates whether productivity at work differs between working PLWH and the working general population in the Netherlands.

**DESIGN** This is a cross-sectional study comparing data of PLWH of one of the main HIV treatment centres in the Netherlands (n=298) with data of the working general population from a previously conducted study (n=986).

**METHODS** The questionnaires used in these studies contained a core of identical questions regarding absenteeism and presenteeism over a four-week period and a variety of baseline characteristics, including health status measured with EQ-5D. For PLWH additional clinical data were collected from patient records.

Descriptive statistics were computed to characterize the samples. Pearson correlations were used to explore significant associations of productivity with baseline characteristics. A two-part model was estimated to evaluate both the occurrence and of size of productivity losses in working PLWH and an aggregated sample of PLWH and the general population.

**RESULTS** We observed that average total productivity losses do not differ significantly between working PLWH and the general working population, but that the occurrence and size of absenteeism and presenteeism were different. Furthermore, more health problems were associated with higher productivity losses. HIV status was not significantly associated with productivity losses.

**CONCLUSION** Among working people, health status was related to productivity losses but HIV status was not. Further research is needed into the relation between HIV status and unemployment.

### Key Words

*Work*

*Productivity  
loss*

*Indirect costs*

*Quality of life*



## Introduction

Due to improving treatment, HIV has turned into a chronic illness. People diagnosed with HIV nowadays have a better prospect of a healthier future than ever before and nearly the same life expectancy as people without HIV.<sup>[1, 2]</sup> However, people living with HIV (PLWH) still face an unpredictable disease course and need to adapt to this.<sup>[3]</sup> As a result, many new challenges emerge, such as issues of occupational functioning and employment.<sup>[4]</sup> PLWH aspire to be part of the workforce in order to be a normal productive member of society, and to increase their personal income.<sup>[5]</sup> However, despite the desire to be productive, many PLWH do not actively pursue labour force participation because of perceived barriers to employment. This prevents them to improve their social functioning and, hence, quality of life.<sup>[6]</sup>

Studies have found several barriers that PLWH experience when thinking of starting or returning to work. These include: general concern regarding loss of government benefits, vulnerability to discrimination, potential mental health complications, concerns regarding job skills, the impact of gaps in one's employment history, and fear of acquiring additional viruses and medical complications that interfere with their ability to work.<sup>[7-9]</sup> In addition, PLWH in the workforce face several problems in persistence at work, in particular those with impaired neurocognitive functioning.<sup>[10]</sup> Fatigue also is an issue among PLWH, with a prevalence of approximately 20 to 60%.<sup>[11]</sup> Finally, comorbidities like diabetes, hypertension and depression have been identified as risk factors for work cessation.<sup>[12]</sup> Employers and policy makers may also be concerned with the labour force participation and productivity of PLWH, albeit for different reasons. There is increasing evidence that, in general, health problems with subsequent functional limitations may cause decreased productivity of workers.<sup>[13]</sup> Such productivity losses may result from absenteeism and presenteeism: if a person is absent from work due to illness, this is called absenteeism<sup>[14]</sup>; if a person is at work, but delivers lower quantity and/or quality of work due to illness, this is called presenteeism.<sup>[15]</sup> In one of the few studies on productivity losses among PLWH, Sendi et al (2004) estimated the mean annual productivity costs per patient at 22,910 Swiss Francs (2002: CHF 1 ≈ EUR 1.47; CHF 1 ≈ US\$ 1.51).<sup>[16]</sup> They found that a higher ability to work was associated with better clinical prognostic factors, such as a younger age, a more recent first positive HIV test, higher CD4 cell count, no history of IV drug use and no history of an AIDS-indicator disease. In this study, a higher education and a stable partnership during the last 6 months were also associated with a higher ability to work.

Further evidence on productivity losses in PLWH is scarce and also little is known about productivity losses in PLWH as compared to those in people with other diseases or in the general population. Consequently, it is difficult to answer the question whether PLWH are less productive at work. Therefore, this study aimed to quantify the productivity losses of PLWH in the Netherlands, explore the main determinants of productivity losses, and compare the results directly with similar data from the general population. Based on the above findings in the literature we hypothesize that gender, education level, marital status, quality of life and several work characteristics influence the height of productivity losses. To our knowledge, there is no sufficient previous literature to sustain a hypothesis about the influence of the diagnosis HIV on productivity.

This paper compares the productivity of a specific group of PLWH with a sample from the general working population in the Netherlands. Hereafter, we will first elaborate on the methods used in this study. Then, the results of our analysis will be discussed, focusing initially on the descriptive statistics of the two separate samples, followed by regressions explaining absenteeism, presenteeism and total productivity losses for the working HIV population as well as the aggregated working sample. Lastly, we discuss the limitations and implications of this work.

## Methods

### Study design

For this study, data from two studies collected through survey questionnaires were used. Data for the PLWH sample were obtained from the baseline measurements of the TREVI project, a longitudinal cohort study with a 2-year follow-up that aims to study cognitive function disorders among PLWH in relation to their employment, productivity, and social functioning.<sup>[17]</sup> Data for the sample from the general working population originate from a study that investigated the relation between health and productivity costs in the Netherlands.<sup>[18]</sup>

### Study populations

The PLWH sample consisted of patients attending the outpatient clinic of the Erasmus Medical Centre in Rotterdam, the Netherlands. Patients were eligible for enrolment if they were 18 years or older and adequately mastered the Dutch language. Patients were excluded if they currently had: an opportunistic central nervous system infection, schizophrenia, a severe affective disorder believed to account for the subject's cognitive impairment, or a neurological disorder such as epilepsy or multiple sclerosis. All 600 eligible patients visiting the outpatient clinic of Erasmus MC between December 2012 and December 2013 were asked to participate; 400 patients showed initial interest and 315 eventually gave informed consent and completed the survey. For comparability with the reference population, 17 respondents were excluded because they were older than 65. From the remaining 298 respondents, 63% had a paid job of at least 12 hours per week at the time of the survey. This study was reviewed and approved by the Medical Ethics Committee of the Erasmus Medical Centre.<sup>[17]</sup>

The reference population consisted of 986 members of the general public in the Netherlands, representative of the adult population (18-65 years) with paid work for at least 12 hours per week in terms of gender, age and level of education. The data were collected in 2010 by a market research organization using an online survey.<sup>[18]</sup>

### Measures

The baseline characteristics gender, age, educational level, marital status, and employment status were collected for respondents in both samples, using the same questions. Education level concerned the highest level of education completed and was divided into three categories: low (no, primary or lower secondary, and lower vocational education), middle (intermediate secondary and middle vo-

cational education), and high (university (of applied sciences)). Marital status was dichotomized as: married/cohabiting versus single (including divorced or widowed). Employment status was dichotomized into having paid employment or not, with being employed defined as having paid work for at least 12 hours per week in both samples.

In both samples, health status was assessed using the EQ-5D.<sup>[19]</sup> This instrument measures health-related quality of life on five dimensions: mobility, self-care, usual activities, pain/discomfort, anxiety/depression. The questionnaire completed by PLWH included the recently introduced 5-level version of the instrument<sup>[20]</sup>, whilst the questionnaire completed by the general population included the original 3-level version.<sup>[19]</sup> The scores of the EQ-5D were used to calculate the misery index, which is the unweighted sum of the dimension levels.<sup>[21]</sup> To make the misery index scores comparable between the two samples, the scores were linearly rescaled to range from 0 to 10, with 0 indicating no health problems and higher scores indicating more health problems.

For all respondents, productivity losses were measured using the iMTA Productivity Cost Questionnaire (iPCQ).<sup>[22]</sup> Absenteeism was assessed by asking respondents whether they had been absent from their work in the past 4 weeks because of illness, and if so, how many days (range 0 to 20). Presenteeism was estimated by asking respondents whether, during the past 4 weeks, there were days they had been at work but they were less productive because of illness. If so, they were asked how many days (range 0 to 20) and which percentage of their usual work they had been able to perform during those days (range 0 to 100). Total productivity losses in the past four weeks were computed by aggregating the number of days absent and the number of days with presenteeism multiplied by the percentage of work not performed on those days. Finally, productivity costs were computed by multiplying the total productivity loss (in hours) of respondents by their hourly wage rate (derived from the monthly wage rate question).

Finally, for characterizing the specific group of PLWH included in this study, their cognition was measured by extending the EQ-5D with a cognition dimension<sup>[23]</sup>, clinical data (CD-4 count, CD-4 nadir, and viral load) were obtained from their patient records, and a question about when the respondent was diagnosed with HIV was included in the questionnaire.

## Statistical analyses

A number of irregularities were observed in the data from the PLWH sample. First, four missing values for how many months had passed since their diagnoses were replaced with the median of their age group (in 10-year brackets). Secondly, 20 respondents who ticked the box 'other' (rather than the options married, living together, single (never married), divorced and widowed) when asked about their marital state were classified as being 'single'. Thirdly, three of the forty-two respondents reporting absenteeism and one of the fifty-one respondents reporting presenteeism did not indicate for how many days. For these respondents, the mean of the other respondents' length of absenteeism or presenteeism was taken as an approximation. Finally, missing income information for fifteen respondents reporting to be in paid employment was approximated using multiple imputation.<sup>[24]</sup> In addition, for the calculation of productivity losses the workweek was maximized at five working days and sixty working hours. Eight respondents in the PLWH sample and forty-eight in the general popu-

lation sample reported more than 20 days of absenteeism and presenteeism in total over the past four weeks, and eight respondents in the general population sample reported to work more than 60 hours per week; these values were truncated.

Baseline characteristics and productivity losses in the two samples were inspected using descriptive analysis (i.e., means, distributions, proportions, etc.). We used Pearson correlations and Fisher exact tests to estimate statistically significant relations between variables. The PLWH, working PLWH and general working population were compared on variables available for all populations, using logit models (see Appendix A). In the analysis of productivity losses, we distinguish the working PLWH population and an aggregated sample, which includes both the working PLWH and the general working population samples. We first used logit models to explore the determinants of the presence of absenteeism and presenteeism. Next, we used two-part models<sup>[25]</sup> to investigate the determinants of the size of productivity losses. To account for non-linear relations, second-degree polynomials were added for every continuous variable.

## Results

### Characteristics of the samples

Table 1 shows the main characteristics of the three samples, PLWH, working PLWH and the general population. Compared to the general working population sample, the PLWH sample as a whole and the working PLWH sample were more often male, older, higher educated, more often single, and reported more health problems (see Appendix A). Within the PLWH sample, cognitive problems and a higher score on the misery index were negatively associated with employment. The working PLWH reported slightly longer workweeks than the general working population: 35.9 [range: 12-40] versus 32.6 [range: 12-60] hours per week.

### Productivity losses

Table 2 shows the productivity losses in the working PLWH and general working population samples. The proportion of working PLWH reporting absenteeism in the past four weeks was lower than in the general working population, but the average number of absenteeism days was higher. For presenteeism, working PLWH reported higher proportions and number of days, but the quantity of work performed on these days was higher (i.e., PLWH reported to have performed 75% of their normal work, the general population 45%). Total productivity losses were very similar between the samples (i.e., 40.1 versus 38.6 hours), whereas productivity costs were larger for PLWH (i.e., €649.5 versus €511.7). This difference results from the higher mean income in the PLWH sample.

**Table 1 Baseline characteristics of our sample**

Variable	Measure	PLWH (n=298)	Working PLWH (n=188)	General population (n=986)
Gender (Female = 1)	%	13.4	11.7	48.8
Age	Mean(SD)	46.9(9.7)	45.9(8.5)	41.3(12.3)
Education Low	%	21.8	17.6	25.4
Education Middle	%	33.9	35.6	42.8
Education High	%	44.3	46.9	31.8
Work hours	Mean(SD)	22.7(17.9)	35.9(5.9)	32.6(9.3)
Income after taxes	€(SD)	-	2,342.59(1,088.03)	1,877.91(1,405.78)
Health a	Mean(SD)	1.24(1.41)	0.78(1.08)	0.64(1.07)
Months since diagnosis	Mean(SD)	91.9(78.5)	79.5(69.1)	NA
Cognitive problems	%	0.41	0.31	NA
Partner	%	51.3	58.0	74.7
Single	%	48.7	42.0	25.3
CD4	Mean(SD)	0.64(0.33) <sup>b</sup>	0.63(0.27) <sup>c</sup>	NA
CD4Nadir	Mean(SD)	0.26(0.17) <sup>b</sup>	0.26(0.17) <sup>c</sup>	NA
Viral Load	Mean(SD)	2.52(1.58) <sup>d</sup>	2.66(1.78)	NA

a Misery index; range 0-10.b n=296. c n=187. d n=297.

**Table 2 Productivity losses in the past 4 weeks**

Variable	Measure	PLWH employed (n=188)	General population (n=986)
Absenteeism	%	22.3	26.2
Presenteeism	%	27.1	20.7
Absenteeism and presenteeism	%	10.6	13.7
Days of absenteeism	Mean(SD; range)	11.05 (19.86; 1-20)	5.31 (4.39; 1-20)
Days of presenteeism	Mean(SD; range)	8.56 (6.20; 1-20)	6.10 (4.84; 1-20)
Quality of work in presenteeism	Mean(SD; range)	0.75 (0.19; 0-1)	0.45 (0.19; 0-1)
Productivity losses (hours, per person)	Mean(SD; range)	40.11 (42.97; 0-160)	38.6 (40.54; 0-228)
Productivity losses (hours, total)		2,928.36	12,621.29
Productivity costs (€, per person)	Mean(SD; range)	649.54 (823.38; 0-3,399.6)	511.7 (616.6; 0-3,749.5)
Productivity costs (€, total)		47,416	167,332

Note: Not all have productivity losses (presenteeism of X days). 4 missing values 'days of absenteeism' -> said to have absenteeism but not how many days. 1 missing values 'days of presenteeism' -> said to have presenteeism but not how many days. Assumption: hours per week/5. Rescaling for > 20 days and those with over 60 hours, assign 60 hours. For income we used Use Multiple Imputation for 16 missing cases (out of 192); we used education, gender and age.

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Table 3 shows that in the aggregated working sample only the level of health problems was associated with productivity losses (in hours), with more health problems leading to higher productivity losses. In the sub-sample reporting absenteeism and/or presenteeism, being female was associated with lower productivity losses, whereas being older, lower educated and having more health problems was associated with higher productivity losses. Being part of the PLWH sample was not significantly associated with productivity losses measured in hours.

**Table 3 Correlations of independent variables with productivity losses (in hours) in aggregated working sample**

	Total sample (n=1,177)	Sub-sample with absenteeism and/or presenteeism (n=400)
HIV	0.03	0.01
Gender [female = 1]	-0.03	-0.16**
Age	0.02	0.21***
Education low	0.03	0.11**
Education middle	0.01	-0.08
Education high	-0.03	-0.01
Partner [yes = 1]	-0.03	-0.04
Health	0.38***	0.26***

Note: \*\*\* = 0.1% \*\* = 1% \* = 5%

The first two models reported in table 4 show that only the level of health problems was negatively associated with the occurrence of absenteeism or presenteeism among working PLWH. Next, the first part of the two-part model, a logit model, shows that the occurrence of absenteeism and/or presenteeism was only associated with age (squared), although with a small coefficient. The second part, a log OLS model, shows that the size of productivity losses in case of absenteeism increased with age and the level of health, but at a diminishing rate (i.e. non-linear relations).

Table 5 shows that in the aggregated sample the occurrence of absenteeism and presenteeism increased with the level of health problems. Furthermore, the occurrence of presenteeism was higher in the PLWH-sample. The two-part model shows that the occurrence of productivity losses in the aggregated working sample was only associated with the level of health problems. The second part of the two-part model (a GLM with Gamma distribution and log-link, as the residuals of the estimated log OLS model were leptokurtic and symmetric) indicates that having more health problems was associated with higher productivity losses (in hours), and that among those who experienced absenteeism and/or presenteeism, females had lower productivity losses. In other words, PLWH more often showed presenteeism, but overall do not show a difference in productivity (losses) measured in hours.

**Table 4 Productivity losses in working PLWH sample**

	<i>Absenteeism<sup>a</sup></i>		<i>Presenteeism<sup>b</sup></i>		<i>Productivity losses</i>			
	<i>(logit model)</i>		<i>(logit model)</i>		<i>(two-part model)</i>			
					<i>Part 1<sup>c</sup></i>		<i>Part 2<sup>d</sup></i>	
	<i>Estimate</i>	<i>S.E.</i>	<i>Estimate</i>	<i>S.E.</i>	<i>Estimate</i>	<i>S.E.</i>	<i>Estimate</i>	<i>S.E.</i>
Intercept	-10.690*	5.132	2.085	4.144	-6.409*	2.892	-9.248*	4.034
Gender [female = 1]	0.655	0.616	0.476	0.587	0.213	0.435	0.747	0.563
Age	0.438	0.231	-0.225	0.188	0.229	0.131	0.566**	0.190
Age (squared)	-0.005	0.003	0.002	0.002	-0.003*	0.001	-0.006**	0.002
Education middle	-0.682	0.587	0.376	0.637	0.593	0.438	-0.933	0.605
Education high	-0.393	0.540	0.667	0.615	0.766	0.422	-0.929	0.547
Partner [yes ==1]	-0.309	0.389	0.486	0.400	0.380	0.303	-0.412	0.351
Health	0.948**	0.342	0.993**	0.365	0.357	0.282	0.969**	0.302
Health (squared)	-0.072	0.061	-0.056	0.079	-0.039	0.057	-0.150**	0.045
Cognitive problems [yes = 1]	-0.153	0.451	0.761	0.430	0.260	0.346	-0.424	0.390
Months since diagnosis	-0.001	0.010	0.008	0.010	-0.001	0.006	0.003	0.009
Months since diagnosis (squared)	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000

Note: \*\*\* = 0.1% \*\* = 1% \* = 5%. a absenteeism yes = 1, no = 0. b presenteeism yes = 1, no = 0. c productivity losses (absenteeism and/or presenteeism) yes = 1, no = 0. d productivity losses in hours (if absenteeism and/or presenteeism = yes).

**Table 5 Productivity losses in aggregated working sample**

	<i>Absenteeism<sup>a</sup></i>		<i>Presenteeism<sup>b</sup></i>		<i>Productivity losses</i>			
	<i>(logit model)</i>		<i>(logit model)</i>		<i>(two-part model)</i>			
					<i>Part 1<sup>c</sup></i>		<i>Part 2<sup>d</sup></i>	
	<i>Estimate</i>	<i>S.E.</i>	<i>Estimate</i>	<i>S.E.</i>	<i>Estimate</i>	<i>S.E.</i>	<i>Estimate</i>	<i>S.E.</i>
Intercept	0.855	-1.587	0.963	-1.854	-0.787	0.828	3.781***	0.616
Working PLWH sample [yes = 1]	-0.214	0.215	0.518*	0.220	0.345	0.196	-0.183	0.145
Gender [female = 1]	0.073	0.151	0.209	0.171	0.107	0.146	-0.246*	0.108
Age	0.013	0.044	-0.009	0.049	0.000	0.042	-0.011	0.032
Age (squared)	0.000	0.001	0.000	0.001	0.000	0.001	0.000	0.000
Education middle	0.184	0.187	0.008	0.204	0.151	0.178	-0.205	0.135
Education high	0.071	0.198	-0.117	0.218	-0.063	0.188	-0.193	0.144
Partner [yes ==1]	-0.035	0.160	0.192	0.181	0.057	0.154	-0.116	0.114
Health	0.932**	0.136	1.280**	0.141	1.147**	0.136	0.272**	0.084
Health (squared)	-0.093**	0.034	-0.115**	0.033	-0.095**	0.035	-0.032	0.018

Note: \*\*\* = 0.1% \*\* = 1% \* = 5%. a absenteeism yes = 1, no = 0. b presenteeism yes = 1, no = 0. c productivity losses (absenteeism and/or presenteeism) yes = 1, no = 0. d productivity losses in hours (if absenteeism and/or presenteeism = yes).

## Discussion

This study is one of the first studies examining the productivity of working PLWH compared to the general working general population. We found that among working PLWH the level of productivity losses was similar to the general working population. Total productivity costs were higher for working PLWH than for the general working population, but this was due to the difference in average income between the samples. Therefore, this study supports previous evidence that HIV has a considerable economic impact due to the indirect costs of productivity losses, but adds to these previous evidence that these productivity losses are not different from those in the general working population.<sup>[26]</sup>

It should be noted that only PLWH receiving HAART were included in this study. Gonzalo et al (2009) argued that due to HAART, PLWH experience a higher quality of life and increased productivity.<sup>[27]</sup> The outcomes might thus be different for other groups of PLWH, in particular those with a worse health situation regarding their HIV. It should also be noted that this study compares productivity between working populations, and that in our sample of PLWH the health of those not working was significantly lower than the health of those working (with misery index of 2.03 and 0.64, respectively; see also Table A2). Possibly the employment rate among PLWH is higher than in the general working population, as described in previous studies<sup>[28-30]</sup>, and because of this, productivity losses/costs could also be higher. In our sample of PLWH, 37% did not have paid employment of at least 12 hours per week. Although this is considerably higher than the unemployment rate at national level, the data we have at our disposal is not suitable to make a direct comparison of the total productivity losses between working PLWH and general population samples (i.e., the differences in productivity at work, as presented here, combined with differences in employment rate because of illness).

In this study, we found that having more health problems was associated with the occurrence of absenteeism and presenteeism among PLWH, and with higher productivity losses. This is consistent with similar studies in other chronic diseases.<sup>[13, 31]</sup> The reported level of health problems was higher among PLWH than among the general population, which can be explained by the increasing burden of comorbidities<sup>[12]</sup> and side effects of medication.<sup>[32]</sup> These side effects have been shown to be associated with work productivity before.<sup>[32]</sup> The level of health problems was also higher among non-working PLWH than among working PLWH, indicating that labour force participation may decrease as disease progresses.

Previous studies described a negative effect of decreased neurocognitive functioning on employment.<sup>[10, 33, 34]</sup> In this study, we did not find a significant relation between cognitive functioning and the level of productivity. This might be due to how problems with cognitive function were measured in this study or the limited variation in cognitive problems among participants in this study, but it could also be that cognitive function has more effect on employment and therefore is less relevant for productivity in a working population, as analysed here. Further research on the relation between neurocognitive functioning and employment is therefore recommended.

For practical reasons, this study focused on PLWH speaking Dutch adequately. However, the total group of PLWH in the Netherlands consists of various ethnicities, who do not always speak Dutch.<sup>[35]</sup>



These PLWH might experience different issues affecting their productivity, such as discrimination because of their ethnicity or limited command of the Dutch language. A reference sample with valid measures for these issues, enabling a similar analysis as presented here, is not available to our knowledge. Further research into these subgroups and their particular problems in the labour market is required.

A limitation of this study is the comparability of the PLWH sample with the reference population. The PLWH sample differed significantly from the general population sample on a number of characteristics relevant for the analysis, and the number of characteristics available in both studies, enabling direct comparison, was limited. In the development of the questionnaire for the current study, a number of measures were selected to improve the comparability between the samples, for example by using the IPCQ for measuring productivity losses and the EQ-5D for measuring health status (although in this study the newer five-level version was used rather than the three-level version used in the reference sample). However, many variables of interest for the current study were not included in the general population sample, or not in sufficient detail. A more extensive measure of cognitive problems is an example. Future research would benefit from working with a larger shared questionnaire.

Another limitation is that this study is based on cross-sectional data and therefore we could only investigate associations, not causal relationships. Furthermore, there may be selection bias in the PLWH sample, as we only included about half of the eligible patients. PLWH functioning better, physically or cognitively, may be better able and more willing to participate in a study about productivity at work, and therefore the collected data may not be representative for the total group of PLWH. Finally, this study addressed only productivity losses at work, not unemployment because of illness. However, we observed a fairly high rate of unemployment among PLWH. In order to understand the total impact of HIV on labour participation, a study addressing both employment and productivity is necessary.

A strong point of this study is the direct comparison of the productivity of PLWH with the general working population. This enabled to explore how productivity losses and its determinants differ between PLWH and others, and showed that productivity losses are similar in both samples and that the level of health problems is the main variable driving productivity losses.

Therefore, this study provides relevant information for counselling and care for PLWH. Here, we found no indication that HIV is associated with additional productivity losses among working PLWH compared to the general public, which stresses the importance of effective treatment. However, HIV may still be related to lower participation in the labour force. Counselling could pay attention to the reasons for not working, including the role of changing health status and factors such as disclosure, stigma and discrimination on the ability to start, return or persevere at work.

In conclusion, this study indicates that working PLWH in the Netherlands overall seem to have the same level of productivity losses as the working general population, with the level of health problems rather than the specific diagnosis HIV as the main determinant. Consequently, proper counselling and care are important for PLWH to function as productive members of society.

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MW contributed to the design of the study, analysis of the data and writing of the manuscript.

MK prepared the data for analysis, and assisted with the data analysis and drafting the manuscript.

PR contributed to the design of the study and provided comments to the data analysis and draft versions of the manuscript.

HM contributed to the design of the study and provided comments to draft versions of the manuscript.

EG contributed to the design of the study and supervised the data collection.

WB contributed to the design of the study and provided comments to the data analysis and draft versions of the manuscript.

JE contributed to the design of the study, supervised the analysis and contributed to writing of the manuscript.

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Appendix A: Comparing the Samples

**Table A1 Comparison of the PLWH and working PLWH samples with the general population (GP) sample (Logit regression)**

Variable	PLWH vs GP	Working PLWH vs GP
Intercept	-2.02(0.36)***	-2.32(0.43)***
Gender [female = 1]	-1.77(0.19)***	-1.86(0.24)***
Age	0.03(0.01)***	0.03(0.01)***
Education Middle	0.12(0.20)	0.38(0.24)
Education High	0.53(0.20)**	0.74(0.23)*
Partner [yes = 1]	-0.96(0.15)***	-0.80(0.17)***
Health	0.40(0.06)***	0.16(0.08)*

Note: dependent variable HIV = 1; GP = 0. \*\*\* = 0.1% \*\* = 1% \* = 5%.

**Table A2 Comparison of the PLWH sample with the working PLWH sample (Logit regression)**

Variable	PLWH vs working PLWH
Intercept	1.84(0.79)*
Gender [female = 1]	0.13(0.42)
Age	-0.01(0.02)
Education middle	0.35(0.37)
Education high	0.35(0.36)
Months since diagnosis	-0.00(0.00)*
Partner [yes = 1]	0.50(0.28)
Health	-0.58(0.12)***
Cognitive problems [yes = 1]	-0.45(0.30)

Note: dependent variable Employed = 1, Unemployed = 0. \*\*\* = 0.1% \*\* = 1% \* = 5%.

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**CHAPTER 7**

Are people living with HIV less productive at work?

# LIVING WITH HIV

Implications for work participation

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## Chapter 8

# HEALTH RELATED QUALITY OF LIFE, PSYCHOLOGICAL FUNCTIONING AND EMPLOYMENT SITUA- TION AMONG PEOPLE LIVING WITH HIV:

The TREVI study  
in Barbados and the  
Netherlands

## CHAPTER 8

Health related quality of life, psychological functioning and employment situation among people living with HIV:  
The TREVI study in Barbados and the Netherlands

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### Abstract

**BACKGROUND** Inter-country comparisons can be important to inform the counselling practices for optimum support of persons living with HIV (PLHIV), depending on societal challenges faced in different countries. The TREVI study compared health related quality of life, psychological functioning and the work situation among PLHIV in Barbados and the Netherlands, two high income countries that are geographically and culturally diverse.

**METHODS** Study participants were recruited from the Ladymeade Reference Unit, Ministry of Health, Barbados (n=165) and the Infectious Disease Outpatient Clinic of Erasmus Medical Center, Rotterdam, the Netherlands (n=315). A self-administered questionnaire examined reported employment, income, general health status, quality of life, happiness, self-care, fatigue, pain, anxiety, depression, and perceptions of stigma and discrimination within personal relationships and the workplace. Cognitive functioning was assessed by a qualified researcher using the International HIV Dementia Scale (IHDS).

**RESULTS** The Barbados cohort was younger (mean age 38yr) and more gender mixed (54% male) compared to the Dutch cohort (48yr, 87% male;  $P<0.05$ ). Both cohorts were well controlled virologically, with 84% of clients in the Netherlands and 85% in Barbados achieving viral suppression  $\leq 200$  copies/ml. The Barbadian cohort scored significantly higher in terms of self-reported quality of life, general health, self-care, activity, mobility, happiness, and depression ( $P<0.05$ ). Cognitive functioning on the IHDS scale was equivalent between the cohorts ( $10.8\pm 1.0$  vs.  $10.8\pm 1.3$ ). Unemployment was 30% in Barbados vs. 35% in the Dutch cohort ( $P<0.05$ ); however, Dutch respondents reported greater job satisfaction and less anxiety ( $P<0.05$ ). Dutch clients were more likely to have disclosed their status to sexual partners, family, work colleagues, and employers. Barbadians were more likely to have been hurt by the reaction of friends to their HIV status (36% vs. 17%;  $P<0.05$ ).

**CONCLUSIONS** The TREVI study has therefore revealed relatively strong resilience among PLHIV living in Barbados in terms of health related quality of life, happiness, and depression. However, willingness to disclose HIV status, anxiety, perceptions of stigma, and workplace satisfaction were better among the Dutch cohort. Understanding the distinct social, workplace and psychological support needs of persons living with HIV in these countries will guide specific health policies to assist reintegration into the workplace and normal daily living for persons after HIV diagnosis.

### Key Words

*HIV*

*Quality of life*

*Stigma*

*Counseling*

*Health policy*



## Introduction

Barbados is a Caribbean country of 284,000 people with a human development index (HDI) of 0.785 - classified as 'high human development' - ranked 57 out of 188 nations by The United Nations Development Programme (UNDP) 1. The Netherlands is a European country of 16.8 Million people with an HDI of 0.922 - classified as 'very high human development' - ranked 5 in the world by UNDP.<sup>[1]</sup> The proportion of adults estimated to be living with HIV in the Netherlands is 0.2% and in Barbados 0.9%.<sup>[2,3]</sup> These country rates are consistent with regional rates, with 0.3% of adults in Europe living with HIV and 1.1% in the Caribbean.<sup>[4]</sup> The gender distribution of HIV infection reported in the two countries shows some similarities and some differences: In both cases the epidemic began in men, but in Barbados (as in the Caribbean region) there is a shift towards new infections in younger women.<sup>[5]</sup> In the Netherlands the epidemic remains focused mostly in gay men, whereas in Barbados it is more mixed, with an estimated 50:50 gay and heterosexual mix of clients attending the national HIV clinic.<sup>[6]</sup> Both countries are affected by HIV clade B.<sup>[2,7]</sup> The introduction of antiretroviral therapy (ART) has led to a marked decline in mortality from HIV. In the Netherlands AIDS cases peaked in 1995 and mortality from HIV has declined since 1994.<sup>[2]</sup> In Barbados AIDS cases and mortality from HIV both declined from a peak in 1998.<sup>[8]</sup> Both countries can demonstrate good virological control among HIV clients retained in care on antiretroviral therapy.<sup>[2,9]</sup>

The challenge in managing HIV in the era of ART has therefore shifted from a matter of life and death to the quality of life experienced by persons living with HIV. This encompasses not just physical functioning, energy and pain, but also mental wellbeing, happiness, anxiety, depression and dementia.<sup>[10-13]</sup> Furthermore, participation in the labor force and issues of absenteeism and presenteeism are important contextual determinants for persons being able to re-integrate into their normal daily routines following HIV diagnosis.<sup>[14-15]</sup> The challenges of stigma and discrimination are recognized within the workplace and family settings, and these create formidable psychological barriers to wellbeing and normal societal functioning.<sup>[16-20]</sup> At a macro-economic level this may translate into loss of competitiveness due to sick leave and disability benefits.<sup>[21,22]</sup> Several studies have described that PLHIV still have a lower employment level than the general population.<sup>[23,24]</sup> However, the underlying mechanisms are sparsely investigated and data on quality of life and daily functioning, including work, is not yet available for many countries. To our knowledge, this is the first study which makes a comparison between two different high-income countries. This may identify differential drivers affecting quality of life and psychological health between countries, leading to improved counseling and local health practice.

We take advantage of two well controlled cohorts with demonstrated HIV virus suppression in Barbados and the Netherlands in order to isolate and compare quality of life and societal barriers that affect daily living for persons with HIV in these countries, in the workplace and at home.

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# Methods

## Study population

Ethical approval for the TREVI study was obtained from the joint Ministry of Health/University of the West Indies Ethical Review Board (ERB), Barbados. The Medical Ethics Committee of the Erasmus Medical Center, Rotterdam, the Netherlands, approved the study as not falling under the scope of the Medical Research Involving Human Subjects Act (WMO). The study complied with The Netherlands Code of Conduct for Scientific Practice from the Association of Universities in the Netherlands (VSNU). The questionnaire was completed online to protect confidentiality of patients and ensure completeness of responses. Results were submitted to a secure server at Erasmus Medical Center, and data were aggregated by country without patient identifiers. Patients were recruited with informed consent from the national HIV clinic in Barbados, The Ladymeade Reference Unit (LRU), Ministry of Health (N=165); and from the Infectious Disease Outpatient Clinic in Erasmus Medical Centre, Rotterdam, the Netherlands (N=315). Recruitment in Barbados took place during 2014/2015 and in Holland during 2012/2013. The Dutch cohort represented a baseline cohort (T0) as part of an ongoing longitudinal cohort study.

## Viral Load

HIV viral load determination in Barbados was performed at the LRU Laboratory, a College of American Pathologists-accredited laboratory, Ministry of Health, using the Roche AmpliPrep® and TaqMan® 48 Analysers (Roche Diagnostics) with a lowest detection limit of 20 copies/ml as described.<sup>[25]</sup> HIV viral load determination in the Netherlands was performed using the COBAS® AmpliPrep/COBAS® TaqMan HIV-1 test (v.2.0) (Roche Diagnostics), also with a lowest detection limit of 20 copies/ml.<sup>26</sup> Results are expressed as median HIV-1 virus copies/ml [inter-quartile range (IQR)] and as the proportion of clients in each cohort suppressed below the CDC threshold value of  $\leq 200$  copies/ml.<sup>[27]</sup>

## Questionnaire

A 127 item on-line questionnaire utilized validated instruments to determine self-reported quality of life, physical and mental health items. The questionnaire was pretested in each country and 100% completion was mandatory through the online format. Instruments included the Medical Outcomes Study HIV Health (MOS-HIV) Survey, an HIV-specific instrument consisting of 35 items addressing ten dimensions of health (overall health, physical functioning, social and role functioning, cognitive functioning, pain, mental health, energy, distress, and quality of life).<sup>[28]</sup> From these ten subscales, two summary scores were created: the Physical Health score and a Mental Health score<sup>[29]</sup>, with higher scores indicating better health related quality of life. Psychological functioning was measured with the anxiety and depression dimensions of the Hospital Anxiety and Depression Scale (HADS).<sup>[30]</sup> The European Quality of Life-5 Dimensions questionnaire (EQ5D) is a non-disease-specific standardized instrument for describing and valuing health-related quality of life, that has been adapted through the addition of cognition as a sixth dimension (EQ5D+). The EQ5D+ dimensions

are mobility, self-care, usual activities, pain, anxiety/depression, + cognition, with each dimension assessed at three levels (no problems, some problems, severe/unable).<sup>[31]</sup> The EQ VAS (Visual Analog Scale) Health and EQ VAS Happiness instruments ask people to indicate where, on a vertical thermometer-like scale ranging from best imaginable to worst imaginable, they think their current happiness or health state should be positioned.<sup>[32]</sup> Study participants were asked if they were in paid employment. Cognitive screening was assessed by a qualified practitioner using the International HIV Dementia Scale (IHDS), an internationally validated screening instrument.<sup>[33]</sup>

**Statistical analysis**

Descriptive data were analyzed for between-group differences (Barbados vs. Netherlands) with bivariate analyses (ANOVA) for numeric and continuous variables and Chi-square analyses for ordinal variables. Statistical significance was assumed at p-value <0.05. For all statistical analyses SPSS software (Version 22.0 for Windows) was used.

# Results

## Demographic and medical characteristics

The age demographic (Table 1) showed a significantly younger cohort in Barbados (mean age 38 years) vs. the Erasmus cohort (48 years,  $P<0.05$ ). The Dutch cohort was overwhelmingly male (87%) and since 85% of respondents were sexually attracted to males one could infer it represented a predominantly male homosexual cohort. The Barbados cohort was significantly more mixed in terms of gender (54% male;  $P<0.05$ ) and sexual preference ( $P<0.05$ ), reporting a blend of sexual attraction to males (73%), females (16%) or both (11%). One third of the Barbados cohort reported the presence of children vs. one fifth in the Dutch cohort (data not shown). Medical data showed that both cohorts were well controlled with respect to HIV-1 viral suppression and recovery from CD4 nadir. Virus level at enrolment into TREVI (median HIV copies/ml [IQR]) was 20 [20; 21.80] in Barbados vs. 20 [20; 52.60] in the Netherlands. In terms of viral suppression  $\leq 200$  copies/ml, 85% of clients achieved suppression below the threshold in Barbados vs. 84% clients in the Netherlands. CD4 at enrolment into the study was  $552 \pm 286$  CD4 cells/ml (mean  $\pm$  S.D.) in Barbados, with a CD4 nadir of  $206 \pm 149$ . In the Netherlands CD4 at enrolment was  $630 \pm 273$  with CD4 nadir  $258 \pm 175$ . Recovery from CD4 nadir was therefore 346 in Barbados vs. 372 in the Netherlands.

**Table 1** Demographic profile of cohorts

Item	Barbados	Holland
Number of persons in cohort n	165	315
Age Years: Mean (range)*	38 (19 - 62)	48 (21 - 73)
Gender (% Male)*	54	87
Sexual Attraction I am attracted to (%)*:		
Males	73	85
Females	16	11
Both	11	4
Marital Status*		
Married or living together (%)	18	45
Single, divorced, or widowed	82	55

\* $p<0.05$ , between groups differences

## Health related quality of life

Quality of life and daily functioning are shown in Table 2. These demonstrate relatively improved perceptions in the Barbados cohort for quality of life, general health, physical functioning, energy and pain by the MOS-HIV survey. Differences were statistically significant for MOS HIV dimensions in quality of life ( $73.9\% \pm 17.1$  Barbados [Mean  $\pm$  S.D.] vs.  $64.9\% \pm 20.2$  the Netherlands;  $P < 0.05$ ) and general health ( $73.3\% \pm 17.8$  Barbados vs.  $66.9\% \pm 19.7$  the Netherlands;  $P < 0.05$ ). These observations were corroborated by the EQ VAS scale, which indicated a significantly better current health state in Barbados ( $7.5 \pm 2.0$ ) compared to the Netherlands ( $6.9 \pm 1.8$ ). Other statistically significantly improved scores ( $P < 0.05$ ) were recorded in Barbados in the EQ5D dimensions of Self-Care, Activity and Mobility (Table 2).

**Table 2 Health related quality of life**

<i>Item</i>	<i>Barbados</i>	<i>Holland</i>
MOS - HIV: quality of life*		
Mean (S.D.) out of 100	73.9 (17.1)	64.9 (20.2)
MOS - HIV: general health*		
Mean (S.D.) out of 100	73.3 (17.8)	66.9 (19.7)
MOS - HIV: physical functioning		
Mean (S.D.) out of 100	90.5 (15.3)	88.1 (14.6)
MOS - HIV: energy		
Mean (S.D.) out of 100	70.6 (17.2)	67.5 (17.8)
MOS - HIV: pain		
Mean (S.D.) out of 100	83.9 (18.4)	83.2 (17.5)
EQ - VAS Health *		
Mean (S.D.) out of 10	8.1 (1.9)	7.0 (1.7)
EQ-5D: self care*		
No problems	99	94
Problems	1	6
EQ-5D: activity*		
No problems	89	64
Problems	11	36
EQ-5D: mobility*		
No problems	90	76
Problems	10	24
EQ-5D: pain		
No problems	55	51
Problems	45	49

\* $p < 0.05$ , between groups differences, SD=standard deviation

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Psychological functioning

Table 3 indicates consistent trends across several instruments towards relatively improved states of cognition, happiness and depression in the Barbados cohort, but with anxiety better in the Dutch cohort. Statistically significant differences were recorded in the HADS Depression and EQ VAS Happiness dimensions in favor of Barbados ( $P<0.05$ ) and HADS Anxiety in favor of the Netherlands ( $P<0.05$ ). Cognitive functioning was assessed by a health practitioner using the International HIV Dementia Scale (IHDS) and was equivalent between the two cohorts ( $10.8 \pm 1.0$  vs.  $10.8 \pm 1.3$  [mean  $\pm$  S.D.]). Correspondingly, a similar proportion of patients in both cohorts (30% vs. 34%) were referred for having a suspected cognitive disorder (data not shown).

Table 3 Mental health, cognition, anxiety, and dementia

Item	Barbados	Holland
MOS - HIV: mental health		
Mean (S.D.) out of 100	74.3 (17.8)	75.2 (15.5)
MOS - HIV: cognitive functioning		
Mean (S.D.) out of 100	86.3 (16.8)	78.0 (16.1)
EQ - VAS Happiness *		
Mean (S.D.) out of 10	7.5 (2.0)	6.9 (1.8)
EQ-5D: cognition		
No problems	68	60
Problems	32	40
EQ-5D: anxiety		
No problems	48	51
Problems	52	49
HADS - anxiety*		
No	63	76
Possible	20	9
Probable	17	15
HADS - depression*		
No	88	81
Possible	9	9
Probable	3	10
International HIV Dementia Scale		
IHDS score: Mean (S.D.)	10.8 (1.0)	10.8 (1.3)

\*p<0.05 between groups differences, S.D.=standard deviation

### **Educational attainment, income and work situation**

Table 4 showed that clients in both cohorts had attained similar education levels. However, there were statistically significant differences in the proportion who were in paid work (70% Barbados vs. 65% Holland) and there was a large pay gap among those in employment. Monthly pay was quoted in local currencies (Barbados Dollars vs. Euros) and a direct comparison was made by converting into US\$: this demonstrated that whereas 79% of the Dutch cohort reported earning  $\geq 1750$  US\$ per month, 84% of the Barbados cohort earned  $\leq 1250$  US\$ per month. The earnings gap was reflected in a statistically higher job satisfaction among Dutch respondents in paid work stating that their job was “in accordance with their educational level” (83% vs. 60%). A significantly greater proportion in the Dutch cohort had attained a management position compared to the Barbados cohort (32% vs. 20%).

**Table 4 Education, employment and income**

<i>Item</i>	<i>Barbados</i>	<i>Holland</i>
Education level Educational level attained (%):		
Low	18	23
Medium	36	34
High	46	43
Paid work*		
Yes (%)	70	65
No	30	35
Income Monthly income (%)*:		
Low (<1500 BD\$ Barbados; <1500 Euro Holland)	67	21
Medium	17	45
High (>2500 BD\$ Barbados; >2500 Euro Holland)	16	34
Management position*		
Yes (%)	20	32
No	80	68
Job in accordance with education level*		
Yes (%)	60	83
No	40	17

\*p<0.05 between groups differences, SD=standard deviation

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Disclosure and stigma

Dutch respondents were more likely to have disclosed their HIV status across family and work-place settings compared to Barbadian respondents (Table 5). However, in both countries there was a notable drop-off for any disclose in the workplace. In the Netherlands any kind of disclosure (to sexual partner, family, colleague, employer) was 87%, 56%, 16%, and 20% in applicable respondents. In Barbados any kind of disclosure to sexual partner, family, colleague, or employer was 53%, 57%, 6%, 7%. Two questions examined perceptions of stigma towards HIV disclosure. The first question “I have been hurt by how people reacted learning I have HIV” was answered in the affirmative by 36% in the Barbadian vs. 17% in the Dutch cohort, a statistically significant difference (P<0.05). The second question “I have lost friends by telling them I have HIV” was answered in the affirmative by 18% in the Barbadian vs. 21% in the Dutch cohort (N.S.).

Table 5 Disclosure

Item	Barbados	Holland
Disclosure to sexual partner (%)*:		
Nobody	40	11
Half-half	21	4
Everybody	24	70
Not applicable	14	15
Disclosure to close family (%)*:		
Nobody	41	42
Half-half	18	6
Everybody	21	48
Not applicable	4	4
Disclosure to colleagues (%)*:		
Nobody	85	73
Half-half	4	2
Everybody	2	12
Not applicable	10	13
Disclosure to employer (%)*:		
Nobody	85	65
Half-half	4	1
Everybody	2	15
Not applicable	9	19

\*p<0.05 between groups differences, SD=standard deviation



## Discussion

This study provides insight into the quality of life, psychological functioning and work situation of PLWH in two high-income countries. The study makes clear that the impact of HIV on daily living is quite distinct between Barbados and the Netherlands, resulting in different outcomes on our variables of interest and implying counseling should be adapted to the local situation.

The older predominantly gay male cohort in the Netherlands and the younger more mixed cohort in Barbados were consistent with known demographic trends for HIV cohorts described in these countries.<sup>[2,4]</sup> The relatively high proportion of respondents in Barbados who indicated bisexual attraction (11%) was higher than in previous surveys (6%), and this has provided new insight into the Barbadian cohort.<sup>[2]</sup> Previous surveys of the cohort had recorded 8% non-response rates to the question on sexual attraction; however, past surveys used words such as “homosexual” that could have been perceived as pejorative.<sup>[3]</sup> The TREVI survey may have benefited from being online, thereby forcing a response to the question, but also in its neutral wording (“I am sexually attracted to: Men / Women / Both”) being able to elicit a more frank response.

Both cohorts reported relatively high rates of unemployment at 30% in the Barbados HIV cohort and 35% in the Dutch cohort.<sup>[34,35]</sup> Relatively greater employment in Barbados is consistent with higher reported scores for quality of life, general health perception, physical functioning, happiness and depression, all of which have been shown to influence the likelihood of employment.<sup>[12-16]</sup> A previous study into chronic diseases in the Latin American - Caribbean region has corroborated that Barbados manifests comparatively low rates of depression.<sup>[36]</sup> It is also possible that the larger size of the informal job sector in Barbados may have blunted any unemployment gap post HIV diagnosis, since the informal sector is estimated to make up 36.7% of GDP in Barbados compared to only 11% in the Netherlands.<sup>[37,38]</sup>

The earnings gap between the two cohorts was quite striking, if not altogether surprising. The very highly developed country status of the Netherlands plus the older age of the Dutch cohort may explain the higher earning power. The majority (84%) of HIV clients attending the national HIV clinic in Barbados earned <300 US\$ per week; this relatively low earning power merits further investigation to determine whether HIV sero-conversion was responsible for the loss in earning potential. While no such information is available for Barbados, research from developed countries has suggested that a 60% drop in income may accompany HIV diagnosis.<sup>[39]</sup> A related concern is that low earning power in a country with a high cost of living, such as Barbados, may impel persons living with HIV to sell sex, whether formally or informally, to boost income. This possible scenario merits further research.

Anxiety in the Barbados cohort was consistently higher than in the Dutch cohort, which might appear at odds with the apparent resilience of the Barbados cohort with respect to general health perception, happiness, depression and self-reported quality of life. However, modest levels of anxiety can be

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linked with beneficial health behaviors, such as in studies with overweight patients following gastric restriction.<sup>[40]</sup> Higher levels of anxiety may also have been related to widespread stigma and discrimination in Barbados identified in this study.

TREVI identified high levels of actual and perceived stigma related to HIV disclosure in both countries, but especially in Barbados and especially in the workplace environment. 36% of the Barbadian cohort had been hurt by how people reacted to learning they had HIV. This compared to 17% in the Dutch cohort. The survey also identified high levels of perceived stigma and discrimination, as reflected in low disclosure rates in all workplace settings. HIV disclosure in the workplace in Barbados remained an almost no-go area with just 6-7% of the cohort having disclosed their HIV status to a colleague or their employer. This confirms previous studies on entrenched negative attitudes towards persons living with HIV (PLHIV) in the workplace in Barbados.<sup>[41]</sup> The problem was not confined to Barbados, however, since low rates of disclosure (16-20%) in The Netherlands spoke to a similar lack of an enabling environment for disclosing HIV status in the workplace. A recent qualitative study in the Netherlands identified widespread discrimination, prejudice and ignorance about HIV in the workplace, with persons living with HIV voicing fears that disclosure could lead to the loss of their job or not getting a job in the first place if disclosed at interview.<sup>[15]</sup> Further workplace education on HIV and strategies to reduce stigma in the workplace are therefore urgently still needed, in both countries.

The investigators acknowledge that these findings remain preliminary with relatively small sample sizes, particularly in Barbados. Further research with a larger sample is therefore warranted to confirm statistical trends in certain dimensions and to identify the determinants of labor force participation. Determinants of employment are under investigation in both countries. This may require further information to be collected into the types of employment engaged in, especially in Barbados which has a large informal self-employed sector.<sup>[37,38]</sup>

In conclusion, the TREVI study in Barbados and the Netherlands has been able to make use of well controlled cohorts to isolate and identify the distinct social, workplace and psychological support needs of persons living with HIV in these countries. Although both are high-income countries, the situation in Barbados and the Netherlands differs significantly and suggests different counseling approaches in each setting. In both countries it remains important in counseling to pay attention to the well-being of PLHIV, also in the work situation, and to investigate work-related concerns. For the Netherlands it is important to discuss the impact of HIV on daily functioning and issues in well-being, such as depression, which may require support by a psychologist for example. This suggests more individual counseling. For PLHIV in Barbados it seems more important to mitigate against anxiety and barriers to disclosure, which suggest more interventions on a societal level, such as campaigns to reduce stigma and discrimination.

**Declarations*****Ethics approval and consent to participate***

Ethical approval for the TREVI study was obtained from the joint Ministry of Health/University of the West Indies Ethical Review Board (ERB), Barbados. The Medical Ethics Committee of the Erasmus Medical Center, Rotterdam, the Netherlands, approved the study as not falling under the scope of the Medical Research Involving Human Subjects Act (WMO). The study complied with The Netherlands Code of Conduct for Scientific Practice from the Association of Universities in the Netherlands (VSNU).

***Consent for publication***

Not applicable

***Availability of data and material***

The datasets used and/or analysed during the current study available from the corresponding author on reasonable request.

***Competing interests***

The authors declare that they have no competing interests.

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No funding was received for this study.

***Authors' contributions***

RCL was involved in conceiving the study, obtaining ethical approval in Barbados and was the lead author in writing the manuscript. MNW was involved in conceiving the study, obtaining ethical approval in the Netherlands, data collection, analysis of the data and contributed to the writing of the manuscript. VL was involved in conceiving the study, obtaining ethical approval in Barbados, and led data collection in Barbados. LWJvD was involved in data collection, data analysis and contributed to the writing of the manuscript. PDDMR was involved in data collection, data analysis and contributed to the writing of the manuscript. HSM was involved in conceiving the study, obtaining ethical approval in the Netherlands and contributed to the writing of the manuscript. ECMvG was involved in conceiving the study, took the lead in coordinating the study across the two sites and contributed to the writing of the manuscript. All authors read and approved the final manuscript.

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## CHAPTER 8

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# LIVING WITH HIV

Implications for work participation

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## Chapter 9

# GENERAL DISCUSSION



## Introduction

This thesis presents a series of studies on HIV and work. Work participation is an important part of everyday life among PLWH. However, PLWH face various work-related issues (including stigma, and physical and mental problems) that have an impact on job retention and return to work. With regard to workability and occupational health, there seems to be a gap between the needs of PLWH and the support provided by various healthcare providers, such as the HIV nurse, HIV physician, and the occupational health physician. It appears that there is a lack of knowledge on the topic ‘working with HIV’.

In light of the objectives of this thesis, the main findings are discussed and new insights are described with respect to the available knowledge on HIV and work. The results of our studies are compared with evidence derived from individuals living with other chronic diseases, and implications for practice and further research are presented and discussed.

## Main findings

The idea for this thesis emerged during the development of the evidence-based, multidisciplinary guideline on ‘HIV and Work’ aiming to improve the vocational counselling for PLWH. For this purpose, a qualitative study investigating the work-related concerns of PLWH in the Netherlands was conducted (**CHAPTER 2**). The main issue reported by the participants was the dilemma of ‘disclosure’, which entails whether or not to conceal their HIV status. Other themes emerging from this study were: stigma and discrimination, lack of knowledge about working with HIV among healthcare professionals, and reduced physical and psychological functioning. These themes then formed the basis for the key questions of the multidisciplinary guideline ‘HIV and work’. The process of the development of this guideline and the main results are described in **CHAPTER 3**. The guideline provides an overview of the available knowledge on HIV and work. Based on the evidence and experiences of Dutch experts, the guideline gives recommendations for the vocational guidance of PLWH.<sup>[1]</sup> The main topics related to the key questions were: the determinants of employment, disclosure and stigma, self-management, and the organisation of care.

Our literature review revealed that, overall, the evidence for most of the key questions was limited. Many of the recommendations were mainly based on expert opinions. Further research was clearly needed to increase the scientific evidence on working with HIV, and to further support the recommendations and guidance for practice. Therefore, we established a number of studies to gain further insight into working with HIV.

One of the topics discussed during the development of the guideline was the role of the HIV nurse in the vocational counselling. Because HIV nurses in the Netherlands play a central role in the counselling of PLWH, various recommendations in the guideline focused on the role of the HIV nurse as a key professional in the vocational guidance. However, so far, it was unclear to what extent HIV nurses



already contributed to the vocational counselling and if this task would fit within their knowledge and competences. **CHAPTER 4** presents the results of a cross-sectional study on the contribution of HIV nurses to vocational counselling. In that study, the nurses stated that they are regularly faced with work-related issues, such as stigma and the dilemma of disclosure. However, they also reported a lack of knowledge and competence with regard to various work-related topics, such as rights and legislations. This is probably explained by the lack of competences in their current job profile. The guideline also revealed that disclosure and stigma are important work-related issues for PLWH. Nevertheless, comprehensive insight into the available literature (e.g. data on the level of disclosure and different types of stigma) was lacking. Therefore, we conducted a scoping review on these themes. **CHAPTER 5** presents the results of that study, which show that the available studies were heterogeneous and, in most cases, disclosure and stigma were secondary outcomes. In addition, the level of disclosure at work was low (ranging from 22-50%), mainly due to the fear of stigma. Most PLWH disclosed their HIV status because they wanted to be accepted, or because HIV interfered with their workability. Insight into the underlying mechanisms of disclosure and stigma was lacking in the available studies.

Because data on the level of work participation among PLWH were lacking and the available research on determinants of employment was scarce, a prospective cohort study (the TREVI study) was set up in one of the main HIV treatment centres in the Netherlands. Because that study included only native Dutch PLWH, the results cannot be generalised to all PLWH in the Netherlands. One of the aims of that study was to determine the level of work participation among PLWH, identify associated determinants and gain insight into productivity losses. **CHAPTER 6** presents the results of that study. It shows that the level of work participation (> 1 hour per week) among both PLWH and the general population was 65%. In the age group 40-54 years the level of employment was significantly lower (relative reduction of 6%). The study also shows that age, time since diagnosis, work status at diagnosis, physical functioning, and the score on depression, were determinants that were significantly related to employment.

**CHAPTER 7** presents the results of a study in which data on the productivity among native PLWH were compared with data from the general Dutch population. The study showed that, although PLWH reported more presenteeism, the level of productivity losses was similar to that in the general population. Also, having more health problems was associated with more absenteeism and/or presenteeism in both the HIV population and the general population. The productivity costs of PLWH were higher than those of the general population, but this was due to a higher income in the PLWH population.

Because international data on 'HIV and Work' were scarce, and comparisons between countries with different social, economic and cultural backgrounds are important to identify societal differences, we set up another cohort study in Barbados. Like the Netherlands, this is also a high-income country, but with a different social and cultural setting. In **CHAPTER 8** the results of the TREVI study performed in the Netherlands were compared with those from Barbados. Regarding gender, the cohort of PLWH in Barbados had 54% male, compared with 87% male in the Dutch cohort. Both cohorts reported a

similar level of PLWH without a paid job, i.e. 30% in Barbados versus 35% in the Netherlands. The cohort in Barbados scored better on quality of life, physical functioning and depression, but worse on anxiety and experienced stigma. Although both Barbados and the Netherlands are high-income countries, a significant difference was found on various determinants.

## New insights

This thesis provides valuable insights into different variables that are related to working with HIV. This section compares our results with the insights we gained from the guideline ‘HIV and Work’. In addition, our results are compared with the recently published guideline ‘Chronically ill and work’, and other relevant studies.

### Level of work participation

Among PLWH, various subgroups can be identified, such as native Dutch PLWH, PLWH with another ethnic background, and women. It is important to take into account that our results (Chapter 5) on native Dutch PLWH cannot be generalised to all PLWH in the Netherlands. The level of work participation is probably overestimated, because having a different ethnic background is negatively associated with the employment rate <sup>[2]</sup>. In the Netherlands, in 2013 immigrants had an employment rate of 56% versus 68% among the native Dutch population <sup>[3]</sup>.

This thesis shows that the level of work participation (>1 hour per week) among native Dutch PLWH was comparable with that of the general Dutch population (65%). However, this was not the case for the age group 40-54 years (relative reduction of 6%). Also, among men, there were significant differences between the age groups 20-39 years (relative reduction of 11%) and 40-54 years (relative reduction of 7%). Compared to earlier studies, the overall level of employment was relatively high; however, it is difficult to compare these various results because different definitions were used for ‘work participation’.

For example, in France, Dray-Spira et al. (2007) reported an employment level of 56.7% <sup>[4]</sup> and, more recently, Annequin et al. reported an employment level of 59.6% <sup>[5]</sup>. Another study on HIV and employment in Denmark concluded that PLWH had a lower employment rate compared to the general population (PLWH 69.2%; general population 83.5%) <sup>[6]</sup>. In the Netherlands, compared to individuals with other chronic diseases, the level of work participation among PLWH seem to be relatively high. In 2010, 25% of the people with a chronic disease and/or moderate to severe limitations had a paid job (>12 hours per week) <sup>[7]</sup>.

### Productivity

Health problems together with functional limitations may cause decreased productivity while at work <sup>[8]</sup>. Side-effects of medication (such as diarrhoea) and cardiac conduction abnormalities or comorbidities may be responsible for productivity losses among PLWH <sup>[9]</sup>; however, also fatigue, sadness and anxiety are symptoms often experienced by PLWH <sup>[10]</sup>. Our study (Chapter 7) revealed

that PLWH have the same productivity losses as the general population, but there were differences in the occurrence and extent of absenteeism and presenteeism. The level of health problems (i.e. higher score on the misery index) is the main determinant of these losses, rather than the HIV status itself.

## Background characteristics related to employment among PLWH

Previous studies have demonstrated that gender <sup>[11]</sup>, education <sup>[4, 12]</sup>, ethnicity <sup>[2]</sup>, presence of children <sup>[13]</sup>, and work status at diagnosis <sup>[14]</sup> are associated with employment, whereas the evidence regarding age and education was conflicting. Having a paid job at diagnosis seemed to be positively associated with work status <sup>[14]</sup>; this was confirmed by our studies. Although being female is reported to be negatively associated with employment <sup>[11]</sup>, our study did not confirm this relation (probably due to our male dominated sample). In previous research, the evidence concerning education level was conflicting <sup>[4, 12]</sup>. In our study, education was not associated with employment; however, our sample consisted mainly of middle and higher-educated PLWH. Our study did not confirm that having children was negatively associated with employment. The guideline ‘Chronically ill and work’ <sup>[15]</sup> described a negative association between work status and a higher age, female gender, ethnicity, low education level, and the presence of children. However, this guideline did not describe the association between work status at diagnosis and present work status.

In conclusion, for PLWH, the work status at diagnosis is associated with employment, whereas the evidence for other variables remains conflicting.

## Disclosure and stigma

Many PLWH experienced stigma or discrimination at work, or when returning to work <sup>[16-22]</sup>; the results of our study confirmed this. One of the reasons for stigma was a lack of knowledge about HIV among employers, co-workers, and the healthcare professionals involved. Our scoping review (Chapter 5) provided further insight into these determinants; however, it also showed that the evidence regarding work-related disclosure and stigma was scarce. For example, the available studies on stigma and work made no distinction between the various types of stigma <sup>[23]</sup>. Moreover, research on the level of experienced stigma in the work situation was also limited. Furthermore, it remains unclear what the influence of stigma is on health and well-being at work. Compared to other chronic diseases it is striking that only among individuals with severe mental health problems was stigma reported as a work-related issue in the guideline ‘Chronically ill and work’. This might also be an issue in other chronic illnesses but, apparently, there was insufficient evidence to incorporate this item in the guideline. The dilemma of work-related disclosure was not mentioned at all in the guideline ‘Chronically ill and work’ <sup>[15]</sup>.

In conclusion, disclosure and stigma are work-related issues among PLWH.

## Physical functioning

Physical functioning and the relation to work has been extensively investigated. It is reported that comorbidity, physical limitations, fatigue, a longer period since diagnosis, and side-effects of medication are negatively related to employment <sup>[2, 14, 16-19, 22, 24-26]</sup>. However, it should be taken into account

that most of these latter studies were small, cross-sectional or qualitative studies.

The results of our studies show that reduced physical functioning still bothers PLWH in relation to their work. Our study (Chapter 6) confirmed the negative association between poor physical functioning and work status; however, we did not distinguish between the roles of comorbidity, fatigue, and the side-effects of medication. Also, we did not confirm the association between medical measures (CD4 level, Viral Load) and employment; this might be explained by the availability of effective medication which completely suppresses the virus. However, we did confirm the negative association between a longer period since diagnosis and work status.

In other chronic diseases poor physical functioning, presence of comorbidity, longer period since diagnosis, and fatigue were also associated with work retention and return to work <sup>[15]</sup>.

In conclusion, physical functioning is related to employment among PLWH, as well as among individuals living with other chronic diseases.

### **Psychological functioning**

The (limited) available evidence on the role of depression is conflicting. For example, Lem et al. found no association between depression and employment <sup>[25]</sup>. Others concluded that the existence of depressive symptoms is negatively associated with employment <sup>[14, 27]</sup>. Our study confirms that the existence of depressive symptoms is negatively associated with employment.

In other chronic diseases, such as cancer and heart diseases, depression is also reported to be one of the negative determinants of employment <sup>[15]</sup>.

The previously described negative association between the existence of mental problems and employment, such as distress and fear <sup>[2, 12, 13, 22, 28]</sup>, was not confirmed in our study (Chapter 6).

Previous studies concluded that a decline in cognitive functioning seemed to be a barrier for employment for PLWH <sup>[14, 16, 28-31]</sup>. Also in other chronic diseases, such as cancer, mental illness, and multiple sclerosis <sup>[15]</sup>, there is evidence that the presence of cognitive impairment is negatively associated with work retention and return to work. Although we expected to confirm this association, our study did not confirm that a decline in cognitive functioning is associated with lower work participation.

### **The work situation**

In the available literature, several factors related to the work situation are described as determinants of employment. For example, a lack of workplace adjustments/support, such as sufficient time for medication and medical visits, was a practical barrier in returning to work, or to keep working <sup>[16, 28]</sup>. Also, fear of health damage caused by work was one of the work-related barriers for PLWH <sup>[20, 32, 33]</sup>. In our studies, PLWH confirmed that it was often difficult to combine their work with their illness. For example, they mentioned that it was hard to combine medical visits with their work, and that factors such as fatigue also bothered them at work. The determinants reported here have also been described in the guideline 'Chronically ill and Work' <sup>[15]</sup>. Also, according to that guideline, other work-related determinants, such as support from colleagues and employer, and the physical and mental strain at work, were associated with employment.

### **International comparison**

Our studies in the Netherlands and Barbados revealed similarities and differences with regard to PLWH in two (high-income) countries with a different socio-economic and cultural background. PLWH in Barbados showed resilience in terms of quality of life and happiness, but also perceive more stigma than PLWH in the Netherlands. In both countries, disclosure at work is low. Counselling should be adapted to local determinants and the best practices from both countries can be used.

## **Recommendations for practice**

The multidisciplinary guideline ‘HIV and Work’ provides various recommendations for practice. These recommendations were broadly supported by all professional associations and the patient association involved. This section presents recommendations for practice, based on the main recommendations of the guideline, supplemented with the new insights emerging from the work in this thesis, and the relevant recommendations from the guideline ‘Chronically ill and work’.

### **HIV and Work on the agenda**

First, further insight into the magnitude of work participation and/or work-related issues among PLWH is needed to establish if there is a problem with work participation among PLWH, what the magnitude of this problem is, and the precise nature of the problem(s). A first step should be to register whether PLWH have a paid job, for how many hours, and whether they experience work-related concerns. It is recommended to further investigate those work-related concerns in order to properly address them.

As described in the guideline ‘HIV and Work’ and in the guideline ‘Chronically ill and work’, the attention paid to work participation within health care is inadequate. In order to adjust to both work and health, the employer and healthcare providers need to have more knowledge on the impact of the chronic condition on workability, and on the possibilities for continuation of employment given the right support and workplace adjustments.

As described in a recent Dutch policy report: focusing on possibilities rather than stressing limitations is preferred and stigma should be prevented <sup>[34]</sup>.

Therefore, it is recommended that work participation, as an important part of daily living, should become a part of the daily counselling and treatment of individuals with a chronic disease by the healthcare providers involved. To achieve this, it is recommended to incorporate knowledge and skills on work and health in the education of healthcare professionals, professional profiles, and guidelines. The guideline ‘Chronically ill and work’ recommends that occupational medicine become part of family medicine, and vice versa. With regard to HIV, it is recommended to (at least) incorporate knowledge about occupational medicine in the Master ‘Advanced Nursing Practice’ or the postgraduate ‘HIV Nurse Education’. However, ideally, it should be incorporated in Bachelor nursing studies, and occupational medicine should also be part of the education of other healthcare professionals. Knowledge on HIV should be easily accessible for all healthcare professionals involved. The

work-related position of PLWH will be improved by further disseminating all available knowledge on HIV and work. Examples are: the guideline ‘HIV and Work’, the guideline ‘Chronically ill and work’, relevant rules and legislations, and all types of practical tools (described below) available through websites for PLWH ([www.positiefwerkt.nl](http://www.positiefwerkt.nl), [www.kiza.nl](http://www.kiza.nl), [www.hivnet.org](http://www.hivnet.org)), and also via other channels, such as social media.

### **Tailor-made counselling**

The multidisciplinary guideline ‘HIV and work’ and the guideline ‘Chronically Ill and Work’<sup>[15]</sup> both recommend a tailor-made counselling. It is important to investigate all physical, psychological, social and work-related factors, which might impede work participation. Although the TREVI study showed that, compared to the general population, especially men in the age range 20-54 years have a significantly lower level of employment, our recommendation is to investigate the work situation of every single patient, and especially subgroups which might have additional work-related problems, e.g. immigrants, women and individuals with a low level of education. This is also recommended in the guideline ‘Chronically ill and work’ in which these groups were described as ‘risk groups’ having a greater chance of losing their jobs, or of absenteeism.

Furthermore, it is important to map the stage of the disease because experience from practice shows that every stage requires a different approach. A practical tool for healthcare providers (such as a conversation guide aiming to investigate all aspects of working with a chronic disease) might be useful, such as the checklist ‘Fit for work’<sup>[35]</sup>.

The guideline ‘HIV and work’ and the guideline ‘Chronically ill and work’ both emphasise the importance of self-management of the patient in case of work participation. Our other studies also stress the importance of the locus of control of PLWH and of people with other chronic diseases. Healthcare providers should investigate the opportunities for self-management and support self-management skills if needed. In case of re-integration, a tool is available for individuals with a chronic condition. This tool (<https://www.mijnreintegratieplan.nl/>) provides extensive information on, for example, legislation, possible work adjustments/accommodations, and supports the investigation of reasons for work limitations.

### **How to deal with disclosure and stigma**

The dilemmas of disclosure and (fear for) stigma seem to be important work-related issues for PLWH. As described in the guideline ‘HIV and work’, a societal increase of knowledge about HIV is supposed to contribute to the prevention of (work-related) stigma. For healthcare providers, it is important to be aware of the dilemma of disclosure and stigma at work, and to support PLWH with the decision as to whether or not to disclose, and how to deal with stigma. One of the recommendations in the multidisciplinary guideline ‘HIV and Work’ focuses on the confidentiality of the conversation between the patient and the healthcare provider, and the information they exchange. It is important to stress (also if not explicitly asked by PLWH) that healthcare professionals have professional confidentiality and that the choice to disclose is always the choice of PLWH. A recommendation for

employers is that if they and their colleagues know about the HIV status of one of their employees, it is important that they are vigilant against possible stigma/discrimination, and discuss this in order to reduce stigma and discrimination. Furthermore, it is necessary to take into account whether the patient faces multiple stigmatised identities, such as homosexuality or a different ethnic background. This may need additional counselling or referral to, for example, a psychologist in case of psychological problems.

### Organisation of care

The results of the studies discussed in this thesis show that the responsibilities with regard to work-related concerns among PLWH remain unclear. Evidence on the organisation of care was lacking. In the Netherlands, PLWH and the healthcare providers mentioned the importance of a well-defined referral network. In order to be able to provide proper counselling for people with a chronic illness such as HIV, the responsibilities and competences of the various healthcare professionals involved should be investigated. It is recommended to create a clear referral network and to stimulate inter-professional cooperation.

The multidisciplinary guideline ‘HIV and work’ suggests it is important to appoint a case manager, which might be the HIV nurse. This thesis supports that recommendation, mainly due to the confidentiality and accessibility of the HIV nurse. These nurses are regularly faced with work-related issues among PLWH, such as fear for stigma and the dilemma of disclosure. First, the HIV nurse may play an essential role in the registration of work participation and work-related concerns; although most HIV nurses are aware of work-related issues, uniformity in registration and counselling is lacking. As recommended in the guideline ‘HIV and work’, the Dutch HIV Monitoring system could coordinate this registration. The HIV nurse could also play an important role in identifying work-related issues among PLWH and refer them to occupational healthcare professionals if needed. However, this thesis reveals that HIV nurses experience a lack of knowledge and competences with regard to various work-related topics, such as rights and legislations. This is probably explained by the lack of education which, in turn, implies that additional training in this area is recommended, as also recently described by Frain et al. <sup>[36]</sup>. Furthermore, it is recommended to extend the job profile of HIV nurses with knowledge and skills about vocational rehabilitation.

If the employer is aware of the HIV status of an employee, it is important that information is gained on ‘working with a chronic condition’, for which various tools are available. One of these tools can be used for conversations with an employee with a chronic disease. This conversation guide provides suggestions for topics that will help provide insight into the effect of the chronic condition on employability; this will help employers to focus on possibilities rather than on limitations <sup>[37]</sup>.

Another tool which is available and recommended in the guideline ‘Chronically ill and work’, is the so-called ‘Guideline participatory intervention’ <sup>[38]</sup>. This tool is intended for working people and aims to improve health and safety at work, sustainable employability, and to assist absent employees to return to work. The tool helps employers and employees to identify work-related issues and appropriate solutions, and aims to increase the positive involvement of both the employer and the employee.

## Recommendations for future research

This thesis shows that the available evidence on employment among PLWH in Western countries is still scarce and consists mainly of small, cross-sectional studies. First of all, longitudinal research is needed to determine causal relations between various determinants and employment outcomes. Data on the level of employment and work-related issues are only available for some countries and often for only a specific subgroup; this implies that an overview of the magnitude of the problem is still lacking. In addition, because the majority of PLWH belongs to the labour force, further research on this topic is recommended <sup>[5]</sup>.

As described in this thesis, various subgroups can be identified among PLWH, such as those with a different ethnic background, and women. Various subgroups may face different work-related problems. Because the studies in this thesis focused mainly on Dutch-speaking PLWH and the participants were predominantly male, further investigation of the work situation of immigrants and women is required. Another subgroup which needs further attention in relation to work is the late presenters, i.e. PLWH with a CD4 count below 350 cells/ $\mu$ L presenting for care. In Europe over one-third of all PLWH are late presenters. This implies a delayed start of anti-retroviral medication and explains a significant proportion of deaths from HIV/AIDS in the HAART Era <sup>[39]</sup>. Moreover, late presenters are associated with a higher risk for comorbidities and clinical progression which may impact on daily living, including work. Therefore, further research on this subgroup is recommended.

The role and presentation of work-related stigma needs additional investigation. First, in most of the available studies, stigma was only a secondary outcome. It also remained unclear what the influence of stigma is on health and well-being at work. Therefore, research on work-related stigma and psychological functioning is recommended.

Previous research described a negative association between work status and comorbidity, fatigue, and side-effects of medication. Because most of these studies were small, cross-sectional or qualitative studies it is recommended to investigate these associations in a longitudinal setting.

Declined neurocognitive functioning is associated with reduced functioning at work among persons living with a chronic disease <sup>[14, 16, 28-31]</sup>. However, this association was not confirmed in the studies in this thesis. This might be explained by the method used to measure cognitive function (i.e. the HIV Dementia Scale) or the composition of the sample. Therefore, it is recommended to further examine and identify the level of cognitive problems among PLWH, and the way this is expressed in the various dimensions of neurocognitive functioning. Subsequently, if this association is present, it will be valuable to address the components of work affected by neurocognitive decline. Furthermore, the benefits of employment on neurocognitive functioning should be further investigated. As described by Vance et al., all dimensions of employment (such as learning new skills, social engagement, and purpose in daily life) contribute to preserving neurocognitive functioning <sup>[40]</sup>.



As described in this thesis, there is a lack of available data on the level of work participation and work-related concerns in various countries. Comparison of different countries provides valuable insight into different factors that affect quality of life and vocational functioning. Therefore, it is recommended to carry out studies on HIV and work in different countries, with different socio-cultural and economic settings. A comparison between such countries might also be helpful in developing policy and improving counselling in relation to HIV.

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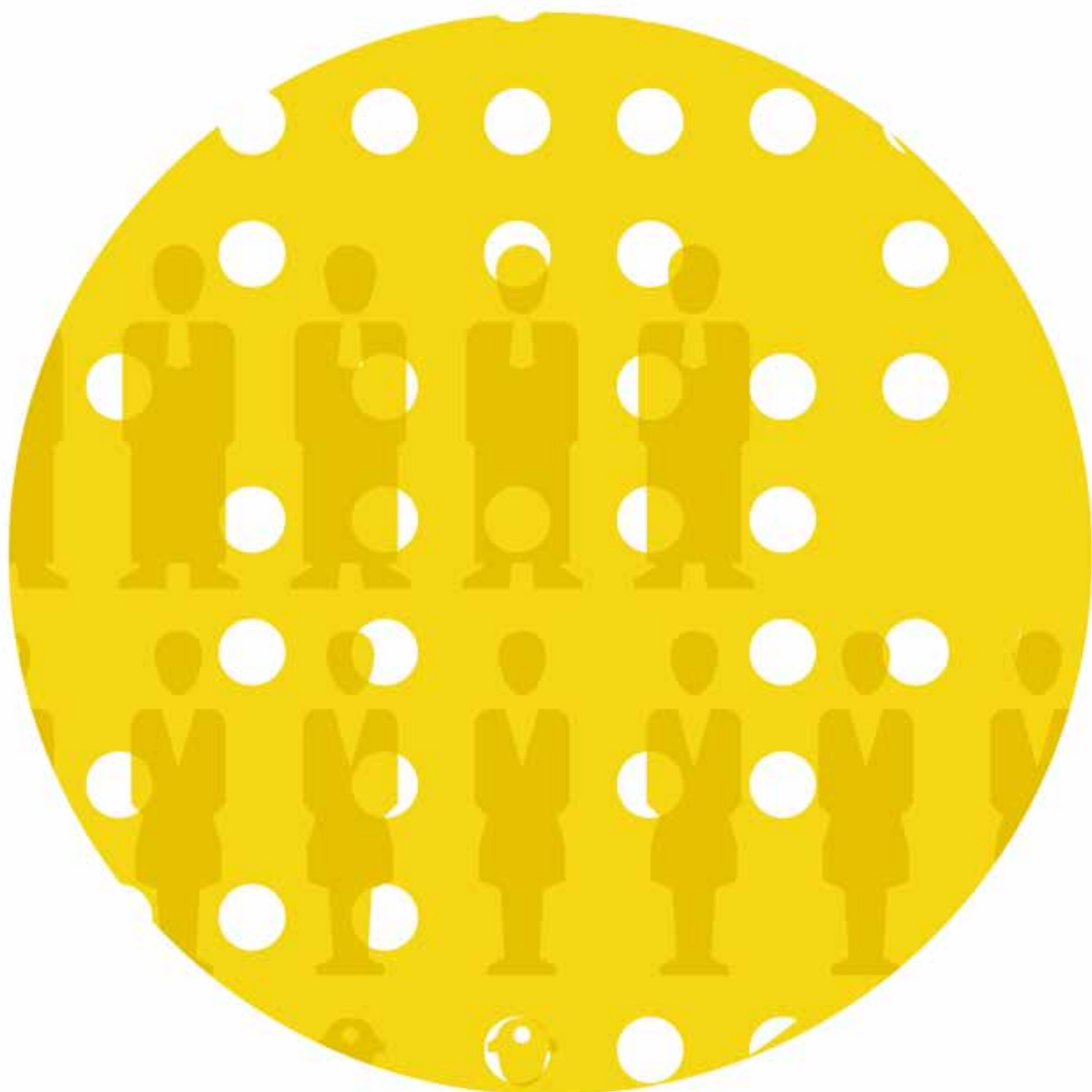
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# LIVING WITH HIV

Implications for work participation

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## Summary



**CHAPTER 1** provides a general introduction. Work participation is an important part of everyday life, also among people living with HIV (PLWH). However, PLWH face various work-related issues, including stigma and mental health problems. Moreover, limited attention is paid to employment during counselling and research on HIV. To support PLWH and their healthcare professionals with work-related problems, a multidisciplinary evidence-based guideline was developed. The first step in the development of this guideline was to establish which topics need to be addressed according to PLWH and then to formulate key research questions.

**CHAPTER 2** presents a qualitative study on the employment-related concerns of PLWH in the Netherlands. The results of this study were used to formulate the key questions for the guideline 'HIV and work'. A total of 18 participants participated in focus group interviews and 9 individual interviews were conducted. The study revealed that the participants faced many work-related issues, such as the dilemma of disclosure and stigma, as well as reduced physical and psychological functioning which have an impact on work.

**CHAPTER 3** describes the development of the multidisciplinary guideline that supports the vocational rehabilitation of PLWH. The guideline was developed according to the 'evidence-based guideline development' method developed by the Dutch Institute for Health Care Improvement. In this process, all relevant professional associations, as well as patient associations, were represented by participating in the core group and in an expert panel. Five key questions for the guideline were formulated with the following themes: i) determinants of employment, ii) disclosure and stigma, iii) self-management, iv) interventions, and v) organisation of care. The literature review included 45 studies, most of them of poor quality. Based on the scientific evidence and considerations from practice, recommendations for daily practice were formulated.

The guideline revealed gaps of knowledge that needed to be investigated. In this thesis, the following gaps were explored: the role of the HIV nurse, work-related disclosure, the level of work participation, related determinants, and productivity losses of PLWH.

A cross-sectional study among HIV nurses (**CHAPTER 4**) investigated their contribution to the vocational counselling of PLWH. Another aim of this study was to compile an inventory of the needs and recommendations for vocational counselling of PLWH. A self-administered survey was used, comprising 25 questions on seven domains: participant characteristics, types of work-related concerns, knowledge and skills for work-related concerns, referral to other professionals, collaboration with other HIV nurses, role of the professional association, and quality of counselling by the HIV nurse. A total of 44 nurses participated in the survey. The results show that HIV nurses regularly faced work-related issues (particularly fear for stigma and discrimination) among PLWH. Participants reported that their knowledge about work-related concerns, especially on rules and legislations, was limited. They also mentioned a lack of competences with regard to facilities at work and career opportunities, and that a clear referral network is needed to improve the vocational counselling by HIV nurses.

**CHAPTER 5** presents a scoping review on work-related disclosure and stigma. Although disclosure and stigma were the main work-related issues for PLWH, insight into available evidence was lacking. Work-related disclosure and stigma were identified in 19 studies but, in the majority of the studies, only as secondary outcomes. It was concluded that disclosure at work was limited (ranging from 22-50%) and that the main reason for non-disclosure was fear of stigma. The studies provided only basic insight into the topic of interest and the available literature was heterogeneous.

The level of work participation among PLWH in the Netherlands is addressed in **CHAPTER 6**. In this study, work participation was compared to the general population, and the determinants of employment related to PLWH were investigated. This study, the TREVI study, reported the baseline measurements of a longitudinal cohort study. Data on the level of work participation and possible determinants of employment (such as physical and mental functioning, work history, and disclosure) were collected via an online survey. Cognitive functioning was screened with the HIV Dementia Scale, and medical data were derived from patient files. The level of work participation was similar for PLWH and the general population (65%) but, among PLWH, particularly the group aged 40-54 years had a significantly lower employment rate. Multivariate analyses showed that age (higher or lower than the reference group 40-54 years), a longer period since diagnosis, problems with physical functioning, and a higher score on depression, were negatively associated with employment. Having paid work at diagnosis was positively associated with employment.

**CHAPTER 7** presents the measurements of productivity of working PLWH (from the TREVI study) and compared these data with data from an earlier study in the general working population. Productivity losses were measured using the iMTA Productivity Cost Questionnaire (iPCQ). Possible determinants of productivity losses which were available for both samples included baseline characteristics (gender, age, educational level, marital status), and health status (measured with the ED-5D). There was no significant difference in productivity losses between PLWH and the general population. More health problems were significantly associated with higher productivity losses, but no with HIV status itself.

Finally, we compared the Dutch situation of PLWH regarding work with another high-income country, Barbados, where attention for daily functioning, including employment among PLWH, is also limited. **CHAPTER 8** presents a comparison of these countries with regard to health-related quality of life, psychological functioning, and vocational functioning among PLWH. The same data as collected for the TREVI study in the Netherlands were collected for Barbados. Comparison of the two countries showed that the Barbadian cohort was younger (38 versus 48 years) and more gender mixed (54% male in Barbados, 87% male in the Netherlands) but that both cohorts were virologically well controlled (84% versus 85%  $\leq 200$  copies/ml). The Barbadian cohort scored higher on quality of life and general health ( $p < 0.05$ ), but Dutch respondents reported less anxiety and greater job satisfaction. Also, compared to the Dutch cohort, the level of disclosure was significantly lower in Barbados and the experienced stigma was higher.

**CHAPTER 9**, the general discussion, starts with a presentation of the main findings. Subsequently, new insights on work participation of PLWH and determinants of employment are described. Finally, recommendations for practice and for future research are presented.

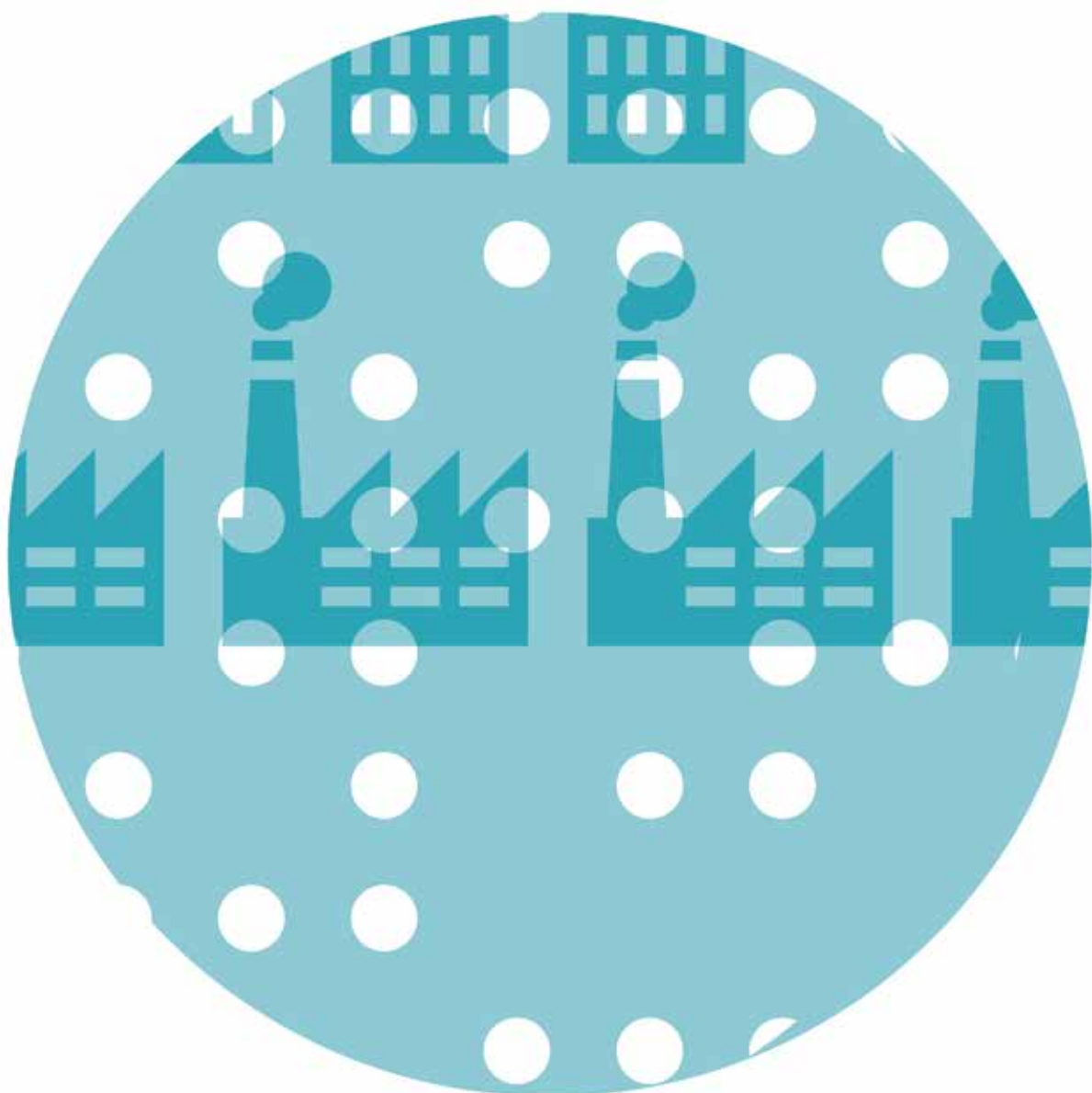


# LIVING WITH HIV

Implications for work participation

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## Samenvatting



**HOOFDSTUK 1** is de algemene inleiding. Arbeidsparticipatie is een belangrijk deel van het dagelijks leven, ook voor mensen met HIV. Mensen met HIV ervaren echter allerlei arbeidsgelateerde problematiek, zoals stigma en mentale klachten. Tot nu toe wordt er relatief weinig aandacht aan arbeidsparticipatie bij mensen met HIV besteed in zorg en onderzoek. Om mensen met HIV en hun zorgverleners te kunnen ondersteunen bij arbeidsgelateerde problematiek is de multidisciplinaire richtlijn HIV en Arbeid ontwikkeld. De eerste stap in de ontwikkeling van de richtlijn was het vaststellen van de onderwerpen die in de richtlijn aan de orde moesten komen. Op basis hiervan zijn de uitgangsvragen voor de richtlijn geformuleerd.

In **HOOFDSTUK 2** wordt een kwalitatieve studie naar de arbeidsgelateerde problematiek van mensen met HIV in Nederland beschreven. De resultaten van dit onderzoek zijn gebruikt om de uitgangsvragen voor de richtlijn HIV en Arbeid te formuleren. In totaal hebben 18 mensen met HIV deelgenomen aan focusgroep interviews en is met 9 mensen een individueel interview afgenomen. Dit onderzoek laat zien dat mensen met HIV allerlei problemen ervaren in relatie tot hun werk, zoals het dilemma om wel of niet open te zijn over de HIV-status, stigma en fysieke en psychische problemen.

In **HOOFDSTUK 3** wordt de ontwikkeling beschreven van de multidisciplinaire richtlijn 'HIV en Arbeid' die als doel heeft om mensen met HIV en betrokken zorgverleners te ondersteunen bij arbeidsgelateerde problematiek. De richtlijn is ontwikkeld volgens de EBRO-methodiek (Evidence-Based Richtlijn Ontwikkeling), ontwikkeld door het Kwaliteitsinstituut voor de Gezondheidszorg CBO. Bij de ontwikkeling van de richtlijn waren alle relevante beroepsverenigingen en de patiëntenvereniging vertegenwoordigd in een kerngroep en een referentengroep. De vijf uitgangsvragen voor de richtlijn bevatten de volgende thema's: determinanten van arbeidsparticipatie, disclosure en stigma, zelfmanagement, interventies gericht op arbeidsparticipatie, en organisatie van zorg. Allereerst werd er een systematisch literatuuronderzoek naar deze thema's uitgevoerd. Er werden 45 studies geïnccludeerd, waarvan het merendeel van beperkte methodologische kwaliteit. Op basis van het wetenschappelijke bewijs en de overige overwegingen vanuit de praktijk, zijn aanbevelingen voor de praktijk geformuleerd.

De richtlijn geeft inzicht in bestaande kennishiaten rondom arbeidsparticipatie bij mensen met HIV. In dit proefschrift is verder ingegaan op de volgende kennishiaten: de rol van de HIV-verpleegkundige, het dilemma van openheid over HIV op de werkvloer, verder inzicht in de mate van arbeidsparticipatie van mensen met HIV en factoren die hierop van invloed zijn.

In **HOOFDSTUK 4** wordt een cross-sectioneel onderzoek beschreven waarin de bijdrage van HIV-verpleegkundigen aan arbeidsgelateerde problematiek bij mensen met HIV is geïncventariseerd. Een ander doel van dit onderzoek was om de behoeften en aanbevelingen te peilen van de HIV-verpleegkundigen op dit terrein. Als meetinstrument is een zelf ontworpen vragenlijst gebruikt die 25 vragen bevatte die de volgende zeven domeinen besloegen: kenmerken van de deelnemers, soorten arbeidsgelateerde problematiek, kennis en vaardigheden met betrekking tot arbeidsgelateerde problematiek, verwijzing naar andere professionals, samenwerking met andere HIV-verpleeg-

kundigen, de rol van de beroepsvereniging, en de kwaliteit van de dienstverlening door de HIV-verpleegkundige. In totaal hebben 44 HIV-verpleegkundigen de vragenlijst ingevuld. De resultaten laten zien dat HIV-verpleegkundigen regelmatig te maken hebben met arbeidsgerelateerde problemen bij hun patiënten, vooral angst voor stigma en discriminatie. De deelnemers gaven aan dat hun kennis op het terrein van arbeidsgerelateerde problemen, vooral met betrekking tot wet en regelgeving beperkt is. Ze gaven ook aan dat ze inzicht misten in mogelijkheden om werk aan te passen en eventuele carrièremogelijkheden. Tot slot gaven de respondenten aan dat meer inzicht onder HIV-verpleegkundigen in mogelijkheden om te verwijzen bijdraagt aan de begeleiding bij arbeidsgerelateerde problemen.

In **HOOFDSTUK 5** wordt een verkennende literatuurstudie (scoping review) beschreven naar disclosure en stigma in relatie tot werk. Hoewel dit belangrijke werkgerelateerde problemen zijn voor mensen met HIV, was er nog geen inzicht in beschikbare wetenschappelijke literatuur op deze thema's. Uiteindelijk bleken 19 studies in te gaan op werkgerelateerde disclosure en stigma maar was het in het merendeel van de onderzoeken een secundaire uitkomstmaat. Er kwam uit de onderzoeken naar voren dat openheid over de HIV-status op het werk beperkt was (22-50%) met als voornaamste reden angst voor stigma. De beschikbare onderzoeken gaven echter maar beperkt inzicht in de twee thema's omdat de studies erg van elkaar verschilden in opzet en uitkomsten.

De mate van arbeidsparticipatie van mensen met HIV in Nederland en factoren die hiermee samenhangen zijn beschreven in **HOOFDSTUK 6**. In dit onderzoek is de arbeidsparticipatie van mensen met HIV vergeleken met de algemene Nederlandse bevolking. Dit onderzoek, de TREVI-studie, geeft de resultaten weer van de eerste meting in een longitudinale cohortstudie. Data voor het onderzoek zijn verzameld door middel van een online vragenlijst waarin allerlei determinanten van arbeidsparticipatie (zoals fysiek en mentaal functioneren, arbeidshistorie, disclosure) zijn geïnventariseerd. Cognitief functioneren is gescreend met de HIV Dementia Scale en medische data zijn opgevraagd uit de patiënten dossiers. De mate van arbeidsparticipatie van mensen met HIV was vergelijkbaar met de algemene bevolking. Echter, bij mensen met HIV, vooral in de leeftijdscategorie 40-54 jaar, was de mate van arbeidsparticipatie significant lager. Multivariate analyses lieten zien dat leeftijd (hoger of lager dan de referentiegroep 40-54 jaar), een langere periode sinds de diagnose, fysieke problemen, en een hogere score op depressie, negatief geassocieerd waren met het hebben van betaald werk. Het hebben van betaald werk op het moment van diagnose was positief geassocieerd met het hebben van werk op dit moment.

**HOOFDSTUK 7** gaat in op de productiviteit van werkende mensen met HIV (vanuit de TREVI studie) en vergelijkt deze data met een eerder onderzoek onder een referentiepopulatie. Productiviteit werd gemeten met de 'iMTA Productivity Cost Questionnaire (iPCQ). Mogelijke determinanten van productiviteit die van beide onderzoekspopulaties beschikbaar waren, waren: algemene kenmerken (geslacht, leeftijd, opleidingsniveau, burgerlijke staat) en gezondheidsstatus (gemeten met de ED-5D). De resultaten lieten zien dat er geen significant verschil in productiviteitsverlies was tussen de

mensen met HIV en de referentiepopulatie. Meer gezondheidsproblemen waren significant geassocieerd met meer productiviteitsverlies, maar de HIV status zelf niet.

Tot slot hebben we de Nederlandse arbeidssituatie van mensen met HIV vergeleken met Barbados. Ook in dit land is aandacht voor het dagelijks functioneren, waaronder werk, van mensen met HIV beperkt. **HOOFDSTUK 8** beschrijft de resultaten van deze vergelijking met betrekking tot kwaliteit van leven, psychisch functioneren, en arbeidsparticipatie bij mensen met HIV in beide landen. Dezelfde data die voor de TREVI studie in Nederland werden verzameld, werden ook verkregen in Barbados. Vergelijking liet zien dat de onderzoekspopulatie in Barbados jonger was (38 versus 48 jaar) en meer gemixt qua geslacht (54% man in Barbados, 87% man in Nederland), maar dat beide populaties succesvol virologisch onderdrukt zijn (84% versus 85%  $\leq 200$  copies/ml). De Barbadiaanse populatie scoorde hoger op kwaliteit van leven en algemene gezondheid ( $p < 0.05$ ), maar de Nederlandse respondenten rapporteerden minder angst en waren meer tevreden met hun werk. Tot slot was de mate van openheid over de HIV status lager op Barbados en ervaren stigma significant hoger.

**HOOFDSTUK 9**, de algemene discussie, begint met een overzicht van de belangrijkste bevindingen van de onderzoeken in dit proefschrift. Vervolgens worden de nieuwe inzichten over mensen met HIV en arbeidsparticipatie beschreven. Tot slot worden aanbevelingen voor de praktijk en toekomstig onderzoek gepresenteerd.



**NIEUWS-  
GIERIGHEID**

**BIJZONDERE  
ONTMOETINGEN**

**NIET  
BANG  
ZIJN**

**OPEN STAAN**

**VERBINDING**

**STEUN**

**DANKBAAR**

**KANSEN**

**INSPIREREND**

**TREVI**

**RESPECT**

**NIEUWE  
INZICHTEN**

**DOOR  
ZETTEN**

VRIENDEN

MOOIE  
REIZEN

GEZELLIGHEID

KOFFIE

LACHEN

PLEZIER

ONTWIKKELEN

VRIJHEID

BARBADOS

GEWELDIGE  
COLLEGA'S

BEDANKT  
VOOR ALLES!  
HET WAS  
TOP!

# Curriculum Vitae

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Marlies Nelleke Wagener

19 februari 1977 Capelle aan den IJssel

marlieswagener@hotmail.com

## Relevant working experience

2009 - present	Lecturer/ Researcher - University of Applied Sciences Rotterdam, Physical Therapy Studies and Research Centre Innovations in Care
2005 - 2009	Care-manager - EMcare, Occupational Outpatient clinic for patient with musculoskeletal complaints, Rotterdam
2003 - 2005	Consultant - KLM Health Services B.V., The Hague
2001 - 2003	Consultant - STOEL, Consultancy in Care and Welfare, Rotterdam
2000 - 2001	Lecturer - Maastricht University
2000	Physical Therapist - Dutch Heart Foundation
1999 - 2000	Physical Therapist - Paramedic Centre Hoppenbrouwers, Roosendaal

## Education

1999 - 2002	Health Sciences - Maastricht University Specialization: Work and Health Graduated 2002
1995 - 1999	Physical therapy Studies - Brabant University of Applied Sciences, Breda Graduated cum-laude 1999
1989 - 1995	VWO - Nassau Scholengemeenschap, Breda





# Portfolio

Name PhD student:
 Marlies Wagener

Department:
 Erasmus MC Rotterdam, Viroscience

PhD period:
 2011 - 2017

Promotor:
 Prof. dr. E.C.M. van Gorp

Copromotoren:
 Dr. P.D.D.M. Roelofs en Dr. H.S. Miedema

<i>PhD training</i>	<i>Year</i>	<i>Workload Hours (ECTs)</i>
<i>Research skills</i>		
Kwalitatieve analyse. Kwalon. Universiteit voor Humanistiek, Utrecht	2010	16 (0,57)
Systematic Review. Belgian Campbell Group. K.U. Leuven	2010	28 (1)
Basisopleiding didactiek HBO. Transfergroep. Rotterdam	2013	280 (10)
Biomedical English Writing and communication. Erasmus MC, Rotterdam	2014	112 (4)
Univariate, bivariate and multivariate analysis; internal training Rotterdam University of Applied Sciences	2014	16 (0.57)
<i>Research groups</i>		
Research meetings Self-management & Participation	2011-2017	20 (0,71)
Research meetings Viroscience Erasmus MC	2011-2017	40 (1,42)
<i>Scientific presentations</i>		
NCHIV. Amsterdam: poster presentation	2011	8 (0,29)
Congres Soa Hiv Seks. Amsterdam: oral presentation.	2011	8 (0,29)
International AIDS Conference. Rome: poster presentation	2011	8 (0,29)
Rode Hoed Symposium presentatie Multidisciplinaire richtlijn HIV en Arbeid. Amsterdam: oral presentation	2012	16 (0,57)
Tweedaagse Praktijkgericht Onderzoek Hogeschool Rotterdam. Rockanje: oral presentation	2012	8 (0,29)
Regionaal Overleg Revalidatie Geneeskunde. Amsterdam: oral presentation	2012	4 (0,14)
Stichting Cirion. Amsterdam: oral presentation	2013	4 (0,14)
CCAS HIV Conference. St. Kitts: two oral presentations and panel.	2015	28 (1)
Abbvie. Innovatie in de HIV-zorg. Veenendaal: oral presentation	2015	8 (0,29)
TREVI Research meeting Erasmus MC. Rotterdam: oral presentation	2015	4 (0,14)
Stichting Cirion. Amstelveen: oral presentation	2016	4 (0,14)
TREVI Research meeting. Boxtel: oral presentation	2016	4 (0,14)
Meeting Jansen Erasmus MC: oral presentation	2016	4 (0,14)

## Conferences attended

EACS. Glasgow	2011	24 (0,86)
NCHIV. Amsterdam	2012/2013	16 (0,57)
ENPHE. Graz	2016	24 (0,86)
Coehre. Sétubal	2017	24 (0,86)

## Other research activities

Scientific work development guideline 'HIV and Work'	2010-2012	1512 (54)
Work visit TREVI Barbados	2015	56 (2)
Organization Zika conference Erasmus MC and Rotterdam University of Applied Sciences	2016	32 (1,14)

## Teaching activities Rotterdam University of Applied Sciences

Minor Arbeid en Gezondheid: module re-integratie	2010-2016	90 (3,2)
Minor Arbeid en Gezondheid: werkgroepen en begeleiding/opdrachtgever studenten bij projecten	2010-2016	120 (4,2)
Minor Arbeid en Gezondheid: workshop kwalitatief onderzoek	2012-2014	8 (0,29)
Minor Wetenschap in de Gezondheidszorg: werkgroepen en begeleiding studenten bij projecten	2012-2017	250 (8,9)
Minor Hoofdzaken en Capitale Beslissingen: werkgroepen en begeleiding studenten bij projecten	2011-2015	200 (7,14)
Minor Hoofdzaken en Capitale Beslissingen: workshop kwalitatief en kwantitatief onderzoek	2012-2016	16 (0,57)
Minor Beyond Borders: opdrachtgever minorproject	2015	8 (0,29)
Keuzevak Mijn Gezondheid de baas: les arbeidsomstandigheden	2010-2017	28 (1)
Ontwikkeling module Externe legitimering	2013	28 (1)
Lecturing Research Skills Physiotherapy	2010-2017	700 (25)
Supervising Bachelor thesis Pysiotherapy	2010-2017	800 (28,5)

# List of publications

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## This thesis

**Wagener MN**, Landis RC, Layne V, Van den Dries L, Roelofs PDDM, Miedema HS, Van Gorp ECM.  
*Health related quality of life, psychological functioning and employment situation among people living with HIV: The TREVI study in Barbados and the Netherlands*  
Submitted

**Wagener MN**, Verbooy K, Kaddouri M, Roelofs PDDM, Miedema HS, Van Gorp ECM, Brouwer W, Van Exel J.  
*Are people living with HIV less productive at work?*  
Submitted

**Wagener MN**, Van Opstal SE, Miedema HS, Van Gorp ECM, Roelofs PDDM.  
*Work-related stigma and disclosure: a daily challenge for people living with HIV. A scoping review of the literature.*  
Accepted for publication in WORK: A Journal of Prevention, Assessment & Rehabilitation.

**Wagener MN**, Van den Dries L, Van exel J, Miedema HS, Van Gorp ECM, Roelofs PDDM.  
*Determinants of employment in people living with HIV in the Netherlands*  
J Occup Rehabil. 2017 Feb 3. doi: 10.1007/s10926-016-9692-8. [Epub ahead of print]

**Wagener MN**, Miedema HS, Kleijn L, van Gorp ECM, Roelofs PD.  
*Vocational counseling of HIV-infected people: A role for nurses in HIV care.*  
J Assoc Nurses AIDS Care. 2015 Jul-Aug;26(4):330-9. doi: 10.1016/j.jana.2015.03.001.

**Wagener MN**, Roelofs PD, Miedema HS, Brandjes DP, Dahmen R, van Gorp EC.  
*The development of a multidisciplinary, evidence-based guideline for "HIV and work". AIDS Care.*  
2015;27(2):133-41. doi: 10.1080/09540121.2014.952612.

**Wagener MN**, van Opstal SE, Miedema HS, Brandjes DP, Dahmen R, van Gorp ECM, Roelofs PD.  
*Determinants of employment-related problems; perspectives of HIV-positive people.*  
J Occup Rehabil. 2014 Dec;24(4):790-7. doi: 10.1007/s10926-014-9510-0.

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## Other international publications

Jong E, Oudhoff L, Epskamp C, **Wagener MN**, Van Duijn M, Fischer S, Van Gorp ECM  
*Predictors and treatment strategies of HIV-related fatigue in the combined antiretroviral era. AIDS.*  
2010; 24(10):1387-1405.

## Publications in Dutch

Kuiper C, **Wagener MN**, Roelofs P, Miedema H  
*Arbeidsrelevante rugklachten.*  
In: Klinisch redeneren volgens de HOAC II, Wittink H, Engelbert RHH (red.). 2010

**Wagener MN.**  
*Zicht op samenwerking.*  
Master thesis Health Sciences. Maastricht University, 2002



