Outpatient HIV care in the Netherlands

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One of the most important events in the history of the human immunodeficiency virus (HIV) was the introduction of antiretroviral therapy (cART) in the mid-1990s. As a result of cART, a previously deadly disease turned into a chronic, treatable disease for people with access to HIV care. Moreover, with the capacity of cART to reduce HIV in the blood to the extent that the risk of transmission is negligible, came the hope that the epidemic could be halted. Unfortunately, it soon became evident that far more than the discovery of cART was needed in the battle against the virus. Although expanding access to cART has led to a remarkable decline in AIDS-related deaths and morbidity, HIV continues to be a major public health problem. Each year, HIV claims more than one million lives and there are nearly two million new infections with HIV annually. In the effort towards achieving a world without HIV and AIDS, we must aim to ensure that all infected individuals have timely access to optimal outpatient HIV care.

The question “What is needed to provide optimal outpatient HIV care” is the common theme in this dissertation. In the introductory chapter 1, we discuss what makes the treatment of HIV infection so challenging. We then give a brief overview of the HIV/AIDS epidemic in the Netherlands and describe how the outpatient care for people with HIV is organised. The chapter ends with an outline of the thesis.

In chapter 2, we start off by providing an overview of the previously published research findings that are relevant for this project. To this end, we evaluated studies that looked into the potential impact of healthcare facility and care provider characteristics on the quality of outpatient HIV care. This gave us the insight that, despite the large body of available scientific literature, it is difficult to make conclusions to guide policy for standards of HIV care. Most importantly, the characteristics that were studied, and the outcomes that were chosen to reflect good quality HIV care, were very diverse. For instance, more than 20 outcomes were measured, and the definitions of equivalent outcomes often differed between studies. Moreover, there were aspects of care that, despite being recognized as essential in the treatment of HIV, were rarely assessed. These included matters regarding non-HIV disease (comorbidities), satisfaction with care and health-related quality of life. In our conclusion, we argue that researchers and healthcare providers need to align their study designs. In addition, they need to go beyond HIV-related morbidity, and include patient experiences in the assessment of quality of HIV outpatient care.

In the Netherlands, HIV care is delivered exclusively in specialised HIV treatment centres. In chapter 3, we explored the association between characteristics of HIV treatment centres and the quality of delivered care.
Summary

To assess quality of care we used three measures, namely the proportion of people with HIV that entered care after 2007 and: 1) was still in care ("retention in care"), 2) had started using cART ("cART initiation") and 3) had reached suppression of the virus ("viral suppression"). These measures are steps in what is often referred to as the "cascade of HIV care" and are necessary for a successful treatment of HIV. We observed little variation across the treatment centres in the outcomes “retention in care” and "viral suppression". In contrast, the measure "cART initiation", varied considerably across the treatment centres. Patients in care in centres with accreditation of the health facility, or centres where an internal audit had been performed in the preceding 3 years were more likely to have initiated cART. These findings confirm that these two quality improvement strategies benefit the adherence to clinical guidelines. In addition, the odds of cART initiation were higher in middle-sized and large, compared with small HIV treatment centres (<300 HIV-infected patients), thereby providing additional evidence for a implementing minimum volume (i.e. number of patients in care) requirement for HIV treatment facilities.

The consequences of HIV infection, such as the need for life-long medication or experiencing stigma, can be distressing. Thus, the health-related quality of life (HRQOL) of people with HIV is generally lower than that of the general population. In chapter 4 we assessed how the HRQOL of people with HIV infection compares to that of individuals with other chronic medical conditions. We measured the HRQOL in a nationwide sample of people with HIV (n=331) and compared it to the HRQOL of patients with diabetes type 1 (n=119) and type 2 (n=2114), and rheumatoid arthritis (n=250). Patients with rheumatoid arthritis were the most disadvantaged in terms of physical HRQOL. In addition, the odds of having a poor physical HRQOL in the HIV-infected group were similar to those of the patients with diabetes mellitus types 1 and 2. The mental HRQOL in HIV-infected patients, in contrast, was poor more often than in the other three groups. These findings suggest that mental HRQOL may be more impaired in HIV-positive individuals than in patients with other long-term illnesses. Our second analysis suggests that this particularly applies to people with HIV who were born in sub-Saharan, and people with a poor immunological status. Factors that were associated with having a poor physical HRQOL were a history of AIDS, a longer time since initiation of cART and severe comorbidity. In conclusion, our study findings confirm that mental HRQOL deserves particular attention in people with HIV and suggest that it may be more impaired than in patients with other somatic long-term illnesses.

When assessing quality of care, the opinions and experiences of patients are very important. The purpose of the study in chapter 5 was to identify aspects of care that are of importance to HIV-infected patients in outpatient care in the Netherlands, and to evaluate to which extent the received care meets their expectations. A modified, previously validated questionnaire (QUOTE-HIV), was used to measure preferences and experiences in a nationwide sample of HIV-infected patients (n=331). Being treated by care providers with specific expertise in HIV medicine was considered of greatest importance to the respondents.
In addition, receiving adequate information about treatment options, and the attitude of care provider (taking the patient seriously, and a sympathetic/involved attitude) stood out as important aspects of care. Notably, confidentiality of HIV status at the outpatient clinic was a major concern for patients. Aspects concerning accessibility (flexibility in care and waiting times) were considered important, but evidently of lower priority in our study population than the earlier mentioned items. Experiences were generally positive with regard to the themes that were addressed. However, there was some room for improvement with respect to waiting times at the blood sampling departments, and provision of information regarding treatment (in particular: advantages and disadvantages of regimes, how to take the medication, and possible side effects). In conclusion, HIV-infected patients greatly value having care providers with HIV-specific expertise. In addition, provision of information about treatment options and safeguarding privacy are aspects that deserve continuous attention in the delivery of outpatient HIV care.

Where in the past patients had to take multiple pills, spread throughout the day, there are now combination pills that often enable patients to take one pill per day. Due to expiring patents, the price of separate pills can be considerably lower. Switching to separate pills, therefore, can be considered as a means to save costs. In chapter 6 we assessed the views of people with HIV in the Netherlands on this matter. We asked a nationwide sample of patients who had been using cART for longer than half a year whether they would be willing to switch from one combination pill to multiple pills, once daily, to reduce healthcare costs. The results indicated that respondents did not necessarily oppose switching to multiple pills. Moreover, we found that the duration of cART usage and the region of origin may impact patients’ willingness to switch. Patients who had been taking cART for 15 years or longer were more willing to take multiple pills. Conversely, non-Dutch respondents were less willing to switch. Our qualitative results show that patients (including respondents willing to switch) feel that switching to multiple pills is a step backwards. In addition, the most common concerns appear to be the dosing frequency, efficacy and tolerability of multiple pills. In conclusion, HIV-infected patients do not necessarily oppose the decision to prescribe multiple-tablet regimens instead of single combination pills to reduce healthcare costs. However, the projected savings should carefully be weighed against the inconvenience of multiple pills. Moreover, considering the scarcity of evidence on the efficacy and safety of switching to multiple pills, the outcomes of such switches should be closely monitored over the long term.

In chapter 7, we discuss our most important findings and provide recommendations for outpatient HIV care. We have observed that high levels of retention in care and viral suppression are achievable in settings with good access to (HIV) treatment and cART. We recommend applying a minimum volume criterion for HIV treatment centres, as is the case in the Netherlands. In addition, we advise to regularly measure performance of HIV treatment facilities using evidence based indicators. Furthermore, there is a need to reassess whether the mental health screening and treatment policies of HIV treatment centres are optimal in the Netherlands.
Summary

Finally, in combating the epidemic, it is crucial that people with HIV are diagnosed and linked to care at an earlier stage of infection. HIV care providers can play an important part in achieving this.