Knowledge gained through experience in young problem drug users: reflections on interventions and change

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Chapter 7

Drug users and HIV-combination therapy (HAART): Factors which impede or facilitate adherence

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Abstract

The current highly active antiretroviral therapy (HAART), i.e., triple combination treatment including a protease inhibitor, allows for long-term suppression of HIV-replication. The intake guidelines, however, are very strict and, like many other HIV positive patients, drug users have problems in achieving good therapy compliance. As a result, the effectiveness of the medication therapy is seriously jeopardized. This qualitative study, involving in-depth interviews with 27 “hard drug” users in Amsterdam, seeks to provide better insights into the extent of adherence to HAART. In addition, factors that impede or facilitate adherence have been listed in order to develop and improve strategies.

The study showed that almost half of the “hard drug” users interviewed do not adhere to the therapy. A large number of determinants for adherence were identified at the level of medication, the individual and the environment.

From the results of this study it is concluded that many of these determinants can be influenced, which means that they can provide clues for the effective implementation of measures that may enhance effectiveness of treatment.
7.1 Introduction

The current highly active antiretroviral therapy (HAART), i.e., triple combination treatment including a protease inhibitor, allows for long-term suppression of HIV-replication (1,2). It is essential however, that prescribed nutritional guidelines, combination and amount of medicines, and administration times are rigorously adhered to. If antiviral therapy is less than optimal, resistant mutations may develop. As a result, medication therapy may no longer be effective at the level of the individual and resistant strains of HIV could spread (3). Imperfect adherence may be HAART’s Achilles’ heel.

Adherence is a dynamic, complex, multidimensional and bounded (culture-time-place-age) process (3,4). Factors affecting patient adherence include health beliefs about the severity of and susceptibility to the disease, and psychosocial factors, as well as the complexity, effects, and costs of the regimen (5,6). It involves more than remembering to take pills at the correct times and in the right amounts, it also requires making and keeping appointments, following advice on diet and activity and altering family schedules. Evaluation of adherence should consider the minimum threshold of therapy necessary for effectiveness. Generally speaking, patients who adhere to their prescribed medical regimen ≥ 80% of the time may be considered to show high adherence, whereas those patients who demonstrate 50% adherence may be demonstrating moderate or low adherence (1). This threshold of therapy depends on the type of illness and of the medicine prescribed. With HAART, however, the threshold for therapy to be effective is 90% (1), or even 95% (7) according to a recent study.

The high minimum threshold for HAART has important consequences for “hard drug” users (intravenous and non-intravenous users of either heroin, cocaine, amphetamine, or methadone). Studies show that “hard drug” users (HDUs) are relatively often excluded from HAART in advance, due to the fact that they are expected to show poor adherence (8,9,10). This is confirmed by data from the Amsterdam cohort study which showed that only 39% of HIV-positive HDUs with a CD4-cell count of ≤ 500 had started combination therapy. Initiating combination treatment appears to be a trade-off between decreasing CD4⁺ levels, increasing HIV-1 RNA levels, and expected compliance. However, among HDUs the balance appears tipped towards delaying the start of HAART compared to other HIV-risk groups such as homosexual men because of expected nonadherence (11). Other studies show that HDUs do have a low level of adherence (12,13,14). Nonadherence to antiretroviral therapy compromises the effectiveness of therapy but is not restricted to HDUs alone (12,15,16,21).

These studies show that HDUs experience a variety of problems in relation to HAART, all of which need to be resolved urgently. For this reason, improvements need to be made in the area of supportive treatment. The aim of the current qualitative study, which focused on HDUs in Amsterdam, was primarily to provide an insight into the extent of adherence to HAART, and secondly, to take a closer look at factors which may impede or facilitate adherence, in order to develop strategies for improvement.

7.2 Method

The Amsterdam Cohort Study among HDUs started in December 1985. Both intravenous and non-intravenous users of either heroin, cocaine, amphetamine or methadone were
invited to participate in this open cohort study (ongoing recruitment). Participants were primarily recruited from methadone posts and also from a special clinic for sexually transmitted diseases (STDs). Those who participated in the study were asked to return every four months for follow-up visits. A questionnaire was completed and a blood test done during each visit (17).

Between March and June 1999, participants in the cohort study who had been using “hard drugs” while initiated on HAART, and who had been on HAART for three months or longer, were approached by research workers to ask if they were willing to participate in the current study. All of the 22 individuals approached participated in the study. Another six participants were recruited at the drug department of the Municipal Health Service. Participation occurred on a voluntary basis, with each participant being paid 25 guilders (about 11 Euro, $10) per interview.

One person (EW) conducted all interviews. Interviews took 75 minutes on average. During these semi-structured, in-depth interviews, all participants were asked to reflect on taking HAART. This was done by focusing on the following three questions: (1) What is the degree of adherence in relation to HAART? (2) Did the individual stop with HAART? If yes: In what way did the individual stop taking HAART? (3) What are the factors which impede or facilitate adherence? All interviews were recorded on tape and transcribed for analysis. Individuals who were still on HAART at the time of their interviews, were also asked to complete the self-reporting questionnaire in relation to the taking of the medication, as used in the Athena project (18). This questionnaire focused on the accuracy of adherence during the week preceding the interview and in the period prior to that. The questionnaire deals with adherence, as recommended by medical authorities, to prescribed nutritional guidelines, to the combination and amount of medicines, and to the times medication was taken.

In order to find an answer to the above questions, it is important to gain familiarity with the motives of interviewees. For this reason the research was carried out in accordance with the grounded theory approach of Glaser and Strauss (19), which entails the systematic development of core constructs which are specific to the area. Central to this approach is the cyclical nature of the research process: the collection of data, qualitative data analysis and reflection, followed by a new cycle.

To assess the extent to which interviewees adhered to antiretroviral therapy, all in-depth interviews were analysed. In case of participants who were still on HAART at time of their interview, analyses of the self-reporting questionnaires were also taken into account. The degree of adherence for each participant was determined based on the previously mentioned minimum threshold of 90%. In practice this means that the error rate for a given patient does not exceed 6 errors per month, where the medication regimen involves medication to be taken twice daily. The word “error” in this context refers to the prescribed nutritional guidelines, the combination and the amount of medicines, and the times medication was taken. When medication was not taken within an hour of the prescribed time of administration we classified the intake as an error. The final assessment for adherence to the treatment regimen was verified by comparing it with known viral load results of the participant originating from the cohort study and from the drug department. If the viral load is not detectable this implies suppression of viral replication.
7.3 Results

Quantitative results
A number of 28 interviews were completed between March and June 1999. One interview was excluded because of contradictory information. The general characteristics of the remaining 27 interviewees are presented in Table 1. The group of interviewees consisted of 16 men and 11 women, with an average age of 40. The youngest participant was 32 years of age and the oldest participant was 50 years of age. All of those who participated in the study were on a methadone program. The ranges of time that the participants had been in methadone treatment are unknown. At the time of their interviews, all participants were under the care of a medical specialist.

Analyses of the interviews and the self-reporting questionnaires revealed that, out of the 27 interviewees, 12 individuals (44.5%), eight men and four women, did not adhere to the treatment regimen (Table 2). In nine cases this was reflected in a detectable viral load. At the time of interviewing, six of these 12 individuals had ceased anti-HIV therapy completely. These six individuals had stopped at their own initiative and were all male. Five of them did not stop the treatment regimen in the correct manner, while one stopped as recommended by medical authorities, i.e., by stopping from one day to the next. The remaining six individuals are still on HAART and do not adhere to the treatment regimen, according to their interview analysis and according to the self-reporting questionnaires. In three cases, this was reflected in a detectable viral load.

The analysis of the interviews and the questionnaires showed that 15 of the 27 interviewees (55.5%, eight men and seven women) had good adherence to the treatment regimen. For two of these individuals, the result could not be verified by means of a viral load assessment, because the latter was not known. Eleven of the remaining 13 individuals did not have a detectable viral load, whilst for two individuals the viral load had reduced by 50% in the preceding 6 months, but was still detectable.

It should also be noted that two out of the 15 individuals stopped taking HAART in the correct manner. One reported that he had stopped because he had gone back on “hard drugs”, after the methadone had been tapered off too fast, while the other individual stopped because of the side effects of HAART.

Qualitative results
Determinants for adherence to the treatment regimen
All but two of the interviewees admitted to have some difficulty in adhering to the HAART treatment regimen. The analysis of the interviews revealed the determinants that impeded or facilitated adherence to the treatment regimen. The various determinants are described in Table 3.

Determinants in relation to the medication
Side effects
Individuals develop problems with HAART because of the many side effects. Although their medical specialist, prior to beginning HAART, informed each patient about side effects, these can be so serious for the person, that the end no longer justifies the means, and that quality of life is impaired. This poses a serious threat to adherence. Interviewees mentioned a total of 17 different side effects. Diarrhoea was a frequently
mentioned side effect and it became apparent from the interviews that diarrhoea may, in severe cases, go on for weeks. The patient will feel extremely uncomfortable and going out will become a problem. In most cases, patients have to resort to wearing diapers and it is important that good antidiarrhoea drugs are used. It is recommended that patients have this type of medication in the house, so as to be able to get temporary relief from symptoms through self-medication. Sometimes diarrhoea is accompanied by nausea, providing a very real risk of dehydration. It is important that patients drink plenty of water (oral rehydration fluid, bouillon made from stock cubes).

Another side effect frequently encountered with HAART is the interaction with “hard drugs”, medicines, and methadone. However, statements in relation to this vary and there seems to be an individual component to interactions. Some interviewees indicated that HAART is simply impossible to combine with “hard drugs”, because they felt unwell when taking both at the same time. Other interviewees felt that interaction between HAART and painkillers, sedatives, and methadone let to the latter being broken down and losing their effect, with all the negative consequences. Methadone in particular was frequently mentioned in this context. Some interviewees got really sick because of the methadone being broken down. Severe withdrawal symptoms were being experienced every day, and sometimes painful feelings which had been suppressed, resurfaced. Due to the unfamiliarity with the problem of interaction, the dose of methadone was not increased in time. Serious complaints persisted and adherence to HAART was at risk. This problem might be solved by a change of HAART medication or by timely increasing the dose of methadone.

Nausea, loss of appetite, and vomiting were also frequently encountered side effects. These complaints may vary from day to day, in relation to their intensity and frequency. In the most serious cases, patients may feel nauseated for hours after taking their medication. If methadone is lost in this way, withdrawal symptoms may develop. Also, the combination of vomiting and loss of appetite may have serious consequences. The analysis revealed that interviewees used various different means to solve these problems. First of all, it is important to have drugs against nausea (anti-emetics) in the house. In addition, there appear to be individual guidelines as to the prevention of nausea and vomiting. These guidelines relate to chronological order, time and posture;

1. Carrying out certain actions in a strictly defined order: *The alarm goes off at 7.30, I make coffee and have a rusk. Then I wash and before I have finished my coffee, I take my medication with some lemonade. Then I go back to sleep.*
2. Carrying out certain actions at a strictly defined time: *Then at a certain point in time, I started taking the Ritonavir 15 minutes prior to the other two, which I took at 8 am. And that worked out perfectly.*
3. Carrying out the actions in a particular posture: *If I lie on my side, everything goes well.*

These individual guidelines were developed through trial and error and became an important ritual for taking the medication with the least possible negative side effects. Lastly, interviewees mentioned smoking marihuana as a way of reducing problems with nausea and loss of appetite. The interviews also revealed that most side effects are exacerbated in the presence of hepatitis and that one should consider deferring HAART in such cases. One interviewee was able to get around the problem by changing the medication regimen for HAART from three pills to be taken twice daily to two pills to be taken three times daily. This would help reduce the load on the liver.
Treatment regimen
Most HDUs have had an irregular lifestyle for years. The analysis of the interviews shows that it is difficult to fit the HAART treatment regimen into this type of lifestyle. A medication regimen where medication has to be taken three times daily causes problems because the midday dose, in particular, tends to be skipped due to the individual's busy schedule of activities. A regimen of twice daily medication does seem feasible. The interviewees thought that a regular lifestyle is important for adherence to the treatment. For this reason it is recommended that every effort should be made to make the medication regimen fit in with the lifestyle to which the individual has been accustomed for years. In that case, the individual can carry on living the accustomed lifestyle, and mealtimes and sleeping patterns will remain more or less the same. In those cases where the individual is addicted to "hard drugs", methadone and/or medication may play a role in regulating the individual's lifestyle. Interviewees gave practical tips to help promote adherence to treatment. A conspicuous looking medication container helps remind the individual of their medication. This also allows the person to check whether they have taken their medication. Having supplies in the form of medication or prescriptions helps prevent the individual from running out of medication unexpectedly. Interviewees often mentioned the use of an alarm clock when mentioning practical tips for helping them take their medication on time. Many of the interviewees indicated that the treatment regimen condemned them to lead a boring and monotonous life. They felt it stopped them from going out spontaneously. Many interviewees solved this problem to some extent by always taking their medication with them. For this reason, it should be easy to keep and transport medication. A covering letter, which explains that the individual is dependent on medication, should be able to prevent problems with the police.

Form and flavour
The form of medication may also lead to problems. Medication should be of a form which is easy to carry around, and for this reason interviewees prefer pills/capsules to liquid medication in a bottle. Larger pills and capsules do have the disadvantage of sometimes sticking in the gullet or to the epiglottis, but these problems can be solved by crushing/opening them. Some interviewees dissolved the content of capsules into water or lemonade. Pills/capsules were also preferred because they tasted better than liquid medication.

Determinants in relation to the individual
Acceptance of the condition
The interviews showed that HAART might be of a highly confrontational nature to those individuals who have not yet accepted the fact that they are HIV positive. HAART not only emphasises the fact that the person is ill, but, in case of HDUs, it also draws attention to the cause of the condition and the drug user's own part in this. In these cases, taking the medication will be accompanied by feelings of denial, fear, anger and guilt. The interviews showed that some individuals did not want to confront this reality and tended to "forget" to take medication in order not to be confronted with unpleasant feelings. According to the interviewees it was important not to start on HAART too quickly and to determine this moment in consultation with the patient. They also felt that it was important to give time and attention to acceptance of being HIV positive.
Cognitive aspects
HAART has not been on the market for very long and little is known about its
effectiveness in the long-term. The interviews showed that interviewees wondered
whether HAART provided any guarantees and whether there was any point in using it.
Interviewees talked about clutching at straws and felt as if they were being used as
guinea pigs. Interviews showed that eliminating these doubts was important for good
adherence. When individuals believe in the effects of HAART and have positive
expectations in this regard, this not only has a positive effect on adherence, but also
means that individuals may be more willing to accept any side effects. If the treatment
has effect, viral load and CD4 cell counts may provide positive feedback.
Self-control also plays an important role in adherence. The interviews revealed that HDUs
who are occupied with their drug use all day long either do not take their medication at
all or take their medication too late. It appears that this form of drug use is not
compatible with HAART. Using hard drugs in a regulated manner can be combined with
HAART. Interviews revealed that the drug use of interviewees who were regular drug
users and who adhered to the treatment regimen varied from using drugs once a day to
using drugs once a month. Interviews also revealed that methadone plays an important
role in either abstaining from drugs or in using drugs, particularly heroin, in a regulated
manner. Methadone ensures that the individual does not get sick and, when taken in high
doses, may even eliminate heroin cravings. One interviewee indicated that he stopped
with HAART when his methadone intake had been tapered off too fast. Interviews also
showed that methadone provides a certain emotional stability because it reduces anxiety
and takes the edge off unpleasant emotions/feelings. Interviewees indicated that the
prospect of urine testing for “hard drugs” might provide an incentive to use “hard drugs”
in a regulated manner but that no one really stopped using “hard drugs” while on HAART.
Finally, self-efficacy is another cognitive aspect that promotes adherence. A feeling of
powerlessness towards disease may have a paralysing effect and may negatively affect
adherence. The analysis of the interviews also showed that adherence is positively
influenced when individual are convinced that they only has themselves to rely on for
survival, and that taking an active attitude gives them power over their condition.

Mental health
It became apparent from the interviews that HIV-positive HDUs often have a hard time.
Sometimes they go through periods where they feel they are not able to cope with and
do not want to carry on living. It became apparent from interviews that individuals
cannot be expected to adhere to HAART seriously when they are going through such
periods of depression, but also that poor adherence may be used as a conscious strategy
for solving life's problems. Feelings of depression have a very negative effect on
adherence. It is recommended that HAART should be combined with antidepressants
when individuals are going through depressive periods. Another option would be for them
to temporarily cease HAART.
Similarly, the analysis showed that self-respect and the ability to enjoy the important and
valuable things in life had a positive influence on adherence. Enjoying doing things,
making things, listening to things and seeing things stimulates adherence.

Knowledge
An insufficient or incorrect knowledge of HAART resulted in poor adherence among
interviewees, sometimes resulting in poor adherence for prolonged periods of time.
Medical jargon and information sheets that were very hard to understand were
mentioned as reasons for this. Interviewees considered adequate knowledge to be a very
important factor for adherence and it became apparent that they felt a particular need for unambiguous answers to the following questions: How many doses am I allowed to miss per month? What should I do when I have missed too many doses? Within how many hours should I take a missed dose? What should I do if I have not taken the missed dose within that time?

Physical health
Users of “hard drugs” who are busy making money and taking dope all day long lead hectic and busy lives. Sometimes they do not get enough sleep and sometimes hygiene leaves much to be desired. Often these individuals do not take enough time to eat and interviews showed that some interviewees had not had a warm meal in years. Hence most HDUs are in a poor physical condition after years of using “hard drugs”. It became clear from the interviews that this poor physical condition was an obstacle for taking HAART because of the many side effects, as a result of which getting enough sleep, eating and drinking well, and good hygiene are important for individuals on HAART.

Material circumstances
Interviewees stated that adherence to HAART cannot possibly be achieved by homeless individuals. It was apparent from the interviews that the type of accommodation interviewees were in varied enormously. Some interviewees lived in their own accommodation while on HAART, whilst others lived with relatives, were in custody, or living in supervised accommodation\(^1\). However, it also became apparent from interviews that not one form of accommodation could guarantee adherence. Even in those cases where individuals were dependent on support staff\(^2\) for receiving their medication, this is no guarantee for adherence. This would seem to be due to pressure of work and ignorance amongst staff.

According to the interviewees, optimal accommodation affects adherence in that it provides shelter, security, peace and quiet, privacy, as well as cooking and eating facilities. Moreover, health care personnel responsible for handing out medication needs to ensure that medication is administered strictly on time. One could consider allowing individuals to self-administer their medication.

In addition, it became apparent from interviews that all individuals concerned were reliant on a minimum benefit, leaving them little financial scope. Apart from spending money on the basic essentials, they often spent money on hard drugs. Even though drug users on HAART often cut back on drugs, money spent on “hard drugs” does mean an extra expenditure. It may be said that HDUs on HAART are often in poor financial circumstances. This may jeopardize their prescribed diet, which is so important in HAART, in turn impeding adherence. It was also apparent from interviews that the part charge of 106 guilders (about € 45, $ 42) to be paid for Viracept is a considerable financial burden, and may negatively affect adherence in the long term. Interviewees were of the opinion that the best way of solving this would be budget management and to do away with the part charges for HAART medication.

\(^1\) Supervised accommodation here refers to accommodation in a residential centre under supervision of health professionals. Residents have their own rooms but shared mealtimes.

\(^2\) The term support staff here refers to staff who supervise and support the drug users, i.e. nurses, social workers and prison guards.
Determinants in relation to the environment

Relationship with health practitioners
Most interviewees indicated that they mainly relied on doctors and nurses to provide them with information, but that they were unable to talk or learn about essential matters in relation to HAART, because doctors and nurses had a negative attitude towards them and because they did not feel they were being taken seriously. This was experienced as discriminatory and demotivating. Interviewees indicated that they wanted to feel respected and that they wanted health practitioners to show some understanding for the problems of addiction. HDUs feel the need to be coached by someone who thinks they are worthwhile, someone who is like a buddy for them, someone who is genuinely interested and concerned, and who takes the time. Continuity plays an important role in this. They want to be able to openly discuss not only their treatment and condition, but also private matters. It was also apparent from the interviews that it is important that questions, concerns, and fears in relation to HAART are eliminated as early on as possible. It is important in this respect to provide easily accessible support that is accessible at all times; this would have a reassuring effect.

Social support
It became clear from the interviews that the presence of trusted individuals positively influences adherence for a number of reasons. Generally speaking, problems that have to do with the treatment and with being HIV-positive are only discussed with trusted individuals, due to embarrassment and fear of isolation. In addition, trusted individuals provide support in that they remind the individual to take their medication and in that they provide accommodation, regularity and meals.

7.4 Discussion
This study has shown that 44.5% of the HDUs interviewed showed poor adherence to HAART. This is a serious development in view of the selection of resistant mutations, as a result of which HAART will no longer work at the individual level and resistant strains of HIV may be transmitted to other people. Nonadherence to antiretroviral therapy, however, is not restricted to HDUs alone. Overall, younger individuals and homeless people also tend to have a poorer adherence to HAART, as well as subjects with depression and lack of self-perceived social support (12,15,16,21). Nonadherence in these groups varied from 40% to 57.7%.
Adherence is a dynamic, complex, multidimensional and bounded (culture-time-place-age) process (3,4) and this study has shown that adherence in HDUs is impeded by determinants to do with the medication itself, the individual and the environment. Strategies put forward by interviewees have been listed.

Side effects which may be worse than the condition itself, a treatment regimen which is difficult to fit in with the irregular lifestyle the drug user has had for years, the form of the medication and the bad taste were mentioned as determinants which have to do with the medication. The interaction of HAART with hard drugs, other forms of medication, and methadone is listed as a side effect. However, statements in relation to the above did not always overlap and there seems to be an individual component to interactions. Generally speaking, interviewees felt that HAART broke down painkillers, sedatives and methadone, leading to serious complaints. One should remain on the alert for this and
dosages may need to be modified. This confirms the findings of Hoetelmans (20) insofar as the interaction of methadone with both protease inhibitors, Norvir en Viracept, is concerned, and it is recommended that the dosage of methadone be increased, based on the observed effect. Nausea and loss of appetite are also listed among the side effects of HAART. The findings of Grinspoon et al. (22,23) were confirmed in that interviewees stated that the medicinal use of marijuana was very effective in this respect. However, this may incur quite high expenditure and interviewees would like to see this covered by health insurance providers. A study by Hulka et al. (24) showed that, generally speaking, adherence decreased as the number of dosages per day increased. This is particularly true when the dosage consists of three or more doses per day (25). HDUs are no exception in this regard and it has become apparent from interviews that a treatment regimen of three doses per day is not really compatible with adherence to HAART.

According to interviewees, denial of one’s condition, insufficient knowledge and cognitive aspects such as doubt about the effectiveness, a high degree of addiction, and feelings of powerlessness are determinants to do with the individual which are an impediment to adherence. Feelings of depression and material circumstances such as accommodation and financial scope also play an important role. This study shows that a severe addiction to “hard drugs” is not compatible with adherence to HAART. However, it does appear that regulated use of “hard drugs” not more than once a day is compatible with adherence, which is in contrast with Besch’s findings (26). Stability and regularity play an important role in this, while the use of methadone and/or other medication may be helpful. This study confirmed findings of studies by Williams, Besch and Ferrando (3,26,27) that feelings of depression have a very negative influence on adherence. There seems to be an important place for antidepressants. In accordance with Bangsberg’s findings (21) these interviews also show that homelessness is not compatible with adherence to HAART. Being in custody or living in supervised accommodation is no guarantee of adherence. This is often due to the heavy workload of the support staff and to their lack of information about the strict intake guidelines for HAART. Specifically educating staff working with HDUs on HAART may show benefits in the short term. A study by Freeman et al. (13) amongst HDUs has shown that uncertainties as to financial recompense negatively influence adherence. This study has shown that the part charge to be paid for Viracept can become a heavy burden, especially when HDUs already find themselves in difficult financial circumstances. Budget management and elimination of the part charge might prove helpful.

Important determinants that have to do with the environment, and that play a role in adherence, are the individual’s relationships with doctors/nurses and social support. Several previous studies emphasised the importance of the doctor/nurse-patient relationship in relation to adherence (1,3). The current study shows that doctors and nurses play an important role in the provision of information on HAART. The findings of O’Conner (28) are confirmed in that, according to interviewees, a negative attitude of doctors and nurses vis-à-vis the drug users is an obstacle to the transfer of information. Adherence would seem to improve when the doctor/nurse-patient relationship involves trust and concern. Showin an understanding for the drug user’s problems, touch, and eye contact are important in this. It is important that there is continuity as to the doctors and nurses involved, and that there is a change of attitudes within these professional groups. When the doctor/nurse-patient relationship is optimal we consider this the right place to deliver facilitating factors for adherence. A study by Haynes et al. (29) shows that the support of family and friends is important for adherence. The findings of this
study concord with that and also show in what way trusted individuals can be of support. Involving social networks in providing support can have a very supportive effect.

Our study, however, has some weaknesses that must be acknowledged. First, our study group may be a selection of all drug users because all of those who participated in the study were recruited within the Municipal Health Service and were on a methadone program at the time of the interview. Although about 72% of heroin users in Amsterdam attends various types of methadone programs, it is not clear to what extent our findings can be generalized to the overall group of HDUs. Second, the interviewees might have given socially-desired answers. We think, however, that potential distortions little influence the conclusion because the interviews were evaluated on their internal inconsistency and because of triangulation of the data: interview, questionnaire and viral load were compared.

We conclude that almost half of the drug users interviewed did not adhere to the treatment regimen. Determinants for adherence have been identified at the level of the medication, the individual and the environment. A large number of these determinants can be influenced, meaning they offer clues for the effective implementation of measures that may support the treatment regimen. This support seems to be needed urgently.
Table 1  General characteristics of the 27 interviewees who participated in the study into adherence to HAART

<table>
<thead>
<tr>
<th>Variables</th>
<th>Patients (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recruitment</td>
<td></td>
</tr>
<tr>
<td>Cohort study</td>
<td>77.7</td>
</tr>
<tr>
<td>Methadone program.</td>
<td>22.3</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
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<tr>
<td>Female</td>
<td>40.7</td>
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<tr>
<td>Male</td>
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<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>30 – 35</td>
<td>14.8</td>
</tr>
<tr>
<td>36 – 40</td>
<td>40.7</td>
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<td>41 – 45</td>
<td>37</td>
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<tr>
<td>46 – 50</td>
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<tr>
<td>Viral load</td>
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<td>&lt; 400</td>
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</tr>
<tr>
<td>400 - 10.00</td>
<td>18.5</td>
</tr>
<tr>
<td>&gt; 10.000</td>
<td>22.3</td>
</tr>
<tr>
<td>unknown</td>
<td>7.4</td>
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Table 2  Self-reported adherence and detectable viral load in 27 interviewees who participated in the study into adherence to HAART

<table>
<thead>
<tr>
<th>Adherence*</th>
<th>Number of individuals</th>
<th>Stopped HAART</th>
<th>Detectable viral load</th>
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</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>NO</td>
<td>12 (44.5 %)</td>
<td>6</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td></td>
<td>-</td>
<td>6</td>
</tr>
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<td>YES</td>
<td>15 (55.5 %)</td>
<td>2</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td></td>
<td>-</td>
<td>13</td>
</tr>
</tbody>
</table>

* Defined on the basis of the in-depth interview and the self-reported questionnaire on medication intake in the period the interviewee was on the therapy
### Table 3  Determinants of adherence in 27 interviewees who participated in the study into adherence to HAART

<table>
<thead>
<tr>
<th>Impeding factors</th>
<th>Facilitating factors</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>MEDICATION</strong></td>
<td></td>
</tr>
<tr>
<td>• -diarrhoea</td>
<td>-diapers, antidiarrhoea medication, fluid supplements</td>
</tr>
<tr>
<td>• -pharmacological interaction</td>
<td>-stop taking hard drugs, change / increase in dose of methadone and other medication</td>
</tr>
<tr>
<td>• -nausea</td>
<td>-anti-emetics</td>
</tr>
<tr>
<td>• -anorexia</td>
<td>-guidelines as to time and order of administration, as well as posture</td>
</tr>
<tr>
<td>• -vomiting leading to withdrawal</td>
<td>-marijuana</td>
</tr>
<tr>
<td>symptoms</td>
<td></td>
</tr>
<tr>
<td>• -therapeutic regimen of three daily</td>
<td>-regime of two daily doses to fit in with lifestyle, regularity, striking drug</td>
</tr>
<tr>
<td>doses</td>
<td>container, supplies, alarm clock, ease of taking medication along.</td>
</tr>
<tr>
<td>• -liquid medication</td>
<td>-pills / capsules</td>
</tr>
<tr>
<td>does not taste nice and is difficult to</td>
<td></td>
</tr>
<tr>
<td>take along</td>
<td></td>
</tr>
<tr>
<td>• -size of pill / capsule</td>
<td>-crush pills and open capsules; dissolving contents in water / lemonade</td>
</tr>
<tr>
<td><strong>PERSONAL</strong></td>
<td></td>
</tr>
<tr>
<td>• -poor acceptance of HIV-positive status</td>
<td>-give time and attention to acceptance of condition. Determine appropriate time for</td>
</tr>
<tr>
<td></td>
<td>commencing HAART in consultation</td>
</tr>
<tr>
<td>• -doubts as to effectiveness of HAART</td>
<td>-positive expectations in relation to HAART and adequate information</td>
</tr>
<tr>
<td>• -irregular use of hard drugs</td>
<td>-regulated use of hard drugs</td>
</tr>
<tr>
<td>• -sense of powerlessness vis-à-vis HIV</td>
<td>-promoting self-efficacy in relation to HIV</td>
</tr>
<tr>
<td><strong>ENVIRONMENT</strong></td>
<td></td>
</tr>
<tr>
<td>• -feelings of depression</td>
<td>-anti-depressants, temporarily ceasing HAART</td>
</tr>
<tr>
<td>• -insufficient / incorrect knowledge</td>
<td>-easy-to-read flyers / easy-to-understand medical language, unambiguous answers</td>
</tr>
<tr>
<td>• -poor physical health</td>
<td>-plenty of sleep / fluid/nutrition, good hygiene</td>
</tr>
<tr>
<td>• -homelessness</td>
<td>-optimal accommodation, supervised if necessary</td>
</tr>
<tr>
<td>• -little financial leeway</td>
<td>-budget management and no part charge to be paid for medication</td>
</tr>
<tr>
<td><strong>ENVIRONMENT</strong></td>
<td></td>
</tr>
<tr>
<td>• -sensing that you are not being taken</td>
<td>-understanding for problems of addiction, respect, taking an interest, concern,</td>
</tr>
<tr>
<td>seriously and negative attitude amongst</td>
<td>continuity, accessible support</td>
</tr>
<tr>
<td>health practitioners</td>
<td></td>
</tr>
<tr>
<td>• -little / no social support</td>
<td>-presence of a trusted individual</td>
</tr>
</tbody>
</table>
References
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7. Paterson, D; Swindells, S; Mohr, J. How much adherence is enough? 6th Conference on Retroviruses and Opportunistic Infections, Chicago, Jan. 31- Febr. 4, 1999.
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