

Starting or Changing Therapy – A Prospective Study Exploring Antiretroviral Decision-Making

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Abstract

Background: When to start or change antiretroviral treatment against HIV infection is of major importance. Patients' readiness is considered a major factor influencing such treatment decisions, in particular because no objective, absolute time point when to start antiretroviral therapy exists. We aimed at evaluating patients' readiness to start or change antiretroviral therapy (ART).

Patients and Methods: HIV-infected patients starting or changing ART between July 2002 and February 2003, treating physicians and nurses participated in this prospective, observational multicenter study. We assessed shared decision-making including qualitative aspects, expected treatment decisions and treatment status after 3 months.

Results: 75 patients were included. Of 34 patients for whom starting ART was considered, 27 (79%) indicated that they were willing to start treatment. After 3 months, 21 of 27 (78%) actually started therapy, six did not. Patients with depression were less likely to be ready for ART ($p < 0.05$). Of 41 patients for whom changing ART was considered, 35 (85%) indicated that they were willing to change treatment. Of the latter 35 patients, 33 (94%) finally changed ART within 3 months. Physicians and nurses were too optimistic in predicting the start or change of ART. The main reason to start or change ART was the sole recommendation of the physician (52% in those starting, 61% in those changing ART). Patients mainly judged the decision as shared and were very satisfied (71%) with the process. Qualitative findings revealed the importance of a dialectic decision-making, described with two categories: "dealing with oneself and others" and "understanding and being understood."

Conclusion: Patients mainly shared the decision made during consultation. Although physicians have an essential role concerning ART, patients, physicians, and nurses all contribute to the decision. Qualitative findings indicate the importance for health-care providers to include patients' expertise and contributions.

Introduction

Potent antiretroviral therapy (ART) has drastically reduced HIV-related morbidity and mortality [1–4]. However, HIV-infected individuals may face new difficulties, mainly related to long-term ART. The question "when to start" or "when to change ART" has become a major issue for HIV-infected individuals and health-care providers. For instance, if providers prescribe ART only at an advanced disease stage, the risk for opportunistic infections and death increases [5]. The prescription of ART at an early stage of HIV infection with a low risk of clinical progression, however, may lead to long-term side effects, possibly low adherence, development of resistance, and high costs. Treatment recommendations provide good assistance, however, as a clear CD4 T-cell threshold at which HIV-infected individuals benefit from initiation of therapy is missing, individualization of treatment decisions is needed [6]. For this reason, physicians and patients must integrate different aspects (e.g. the clinical and psychosocial situation, CD4 T-cell counts, and viral load) and thoroughly weigh risks and benefits of starting ART, in particular when CD4 T-cell counts are between 200/ μ l and 350/ μ l. Similarly, change of treatment is often a very complex decision. Importantly, the patients' readiness to start or change ART is a strong argument to either initiate

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or change ART. Although assumed to be highly important, the readiness of HIV-infected individuals to start or change therapy has been poorly investigated so far. We assume that readiness is the result of a complex treatment decision process. We adapted *Llewellyn-Thomas'* [7] decision-making framework to guide quantitative and qualitative research examining a patient's readiness to start or change ART. Therefore, we explored the process of reaching a final treatment decision from both the patients' as well as the health-care providers' perspective including also the provider-patient relationship.

Patients and Methods

HIV-Infected Individuals and Their Health-Care Providers

This study was performed at three clinics (Basel, Aarau, St.Gallen) participating in the Swiss HIV Cohort Study and one HIV center in Munich (Germany). The Swiss HIV Cohort Study represents a large-scale cohort of HIV-infected patients followed up every 3 to 6 months with laboratory and clinical data recording. Between July 2002 and February 2003, all eligible, i.e. all HIV-infected patients with good knowledge of the German language were enrolled if a start or change of ART was considered. Physicians and nurses caring for a specific patient were also included in the study. Both of them were instructed for at least 60 min about the background, objective, methods and inclusion procedure before the study start. Later on the principal investigator assisted them in unclear situations. Informed consent was obtained from all study participants (patients, physicians, and nurses). Patient characteristics assessed included gender, age, transmission mode, HIV stage, CD4 T-cell count, viral load, and duration of HIV infection at the time of inclusion. In addition, anxiety, depression scores and quality of life were elicited using the HADS-D (Hospital Anxiety and Depression Scale) and SF-8 questionnaires [8–11]. The validated and standardized German version of the HADS-D and SF-8 were used. Important characteristics of physicians and nurses were also assessed (i.e. age, professional experience and the duration of the physician and nurse-patient relationship, respectively). Qualitative in-depth interviews were conducted with 12 patients from the clinic in Basel to further explore their experience of ART decision-making and its influence by physicians and nurses.

Exploring Treatment Decision-Making

We assessed expected treatment decisions immediately after consultation and the actual decision finally made. The issue of treatment decision may have been raised either by the treating physician or by the patient during the consultation. In this situation, physicians were instructed to ask patients to participate in this study. Patients with insufficient knowledge of the German language and patients who had already been enrolled in this study before were not eligible. In fact, the questionnaire was distributed by the physician in the following situations: i) surrogate markers which suggested that a start or change of therapy was indicated, ii) patients were suffering from a concomitant HIV-related disease, iii) patients reported significant side effects or iv) patient wished to start or change therapy even if there were no obvious reasons for a change as viewed by the physician. If any of these four situations were identified, the patient and the physician had to indicate after the consultation whether ART will be started or changed as agreed upon. Alternatively, the patient and physician could state that a patient was uncertain and therefore may start/change ART

at a later time. This was done immediately after the consultation in a separate room for patients and physicians. The reason for a treatment decision from the patient's perspective was elicited using a questionnaire. Patients had to state whether the treatment decision was made by them only, mainly by themselves, together with the physician, mainly by the physician or by the physician only [12].

Physicians and nurses stated whether they would expect the patient to start/change ART. If they considered a treatment start or change before the consultation (i.e. in 71%), they had to answer an additional part of the questionnaire before the consultation with questions about their prediction. Finally, we assessed whether the patient actually started or changed therapy within 3 months after the consultation when the questionnaire was distributed. Following this, patients were classified as either starters, nonstarters, changers or non-changers. Patients without prior antiretroviral therapy or after treatment interruption were categorized as starters if they actually started ART within 3 months or as nonstarters if they did not. Patients already on ART were classified as changers if they actually changed the antiretroviral regimen within 3 months or as non-changers if they did not.

Qualitative Analysis

The qualitative part followed a critical hermeneutic research design which emphasizes communication related to social, political, and cultural influence. A convenient patient sample of 12 patients was recruited from the participants of the quantitative study sample at Basel. Two to 3 months after a treatment decision was made during consultation, in-depth interviews were conducted with these patients. Six patients had considered starting and six changing therapy. All interviews were audiotaped and transcribed verbatim. Data were analyzed and interpreted using the approach of *Diekelmann* and *Allen* [13], i.e. texts were summarized and related themes and categories were identified. Categories were discussed with two independent experienced researchers and one study participant (an interviewed patient). Feedback from these discussions prompted analysis. During the final stage of analysis, categories that appeared in all texts were further refined.

Statistics

The data of this study were analyzed in a descriptive way regarding the decision-making behavior of patients. The differences in the HADS and SF-8 scores between the four patient groups were tested using one-way ANOVA. If the overall p-value was significant ($p < 0.05$), group comparisons were performed using Bonferroni correction.

Results

Patients, Physicians, and Nurses

A total of 81 HIV-infected patients were eligible for inclusion. Of these, 75 patients were included in the study as shown in figure 1 as the entire data set, i.e. all questions answered, was not available in six patients. All but one patient were Swiss Germans or Germans. Of 34 patients without ART (11 patients never had an ART before) for whom physicians and/or patients considered treatment, 27 (79%) indicated at the end of the consultation that they would start treatment and seven indicated that they would not. After 3 months, 21 (78%) patients actually started therapy and 13 did not. Importantly, six patients who decided they

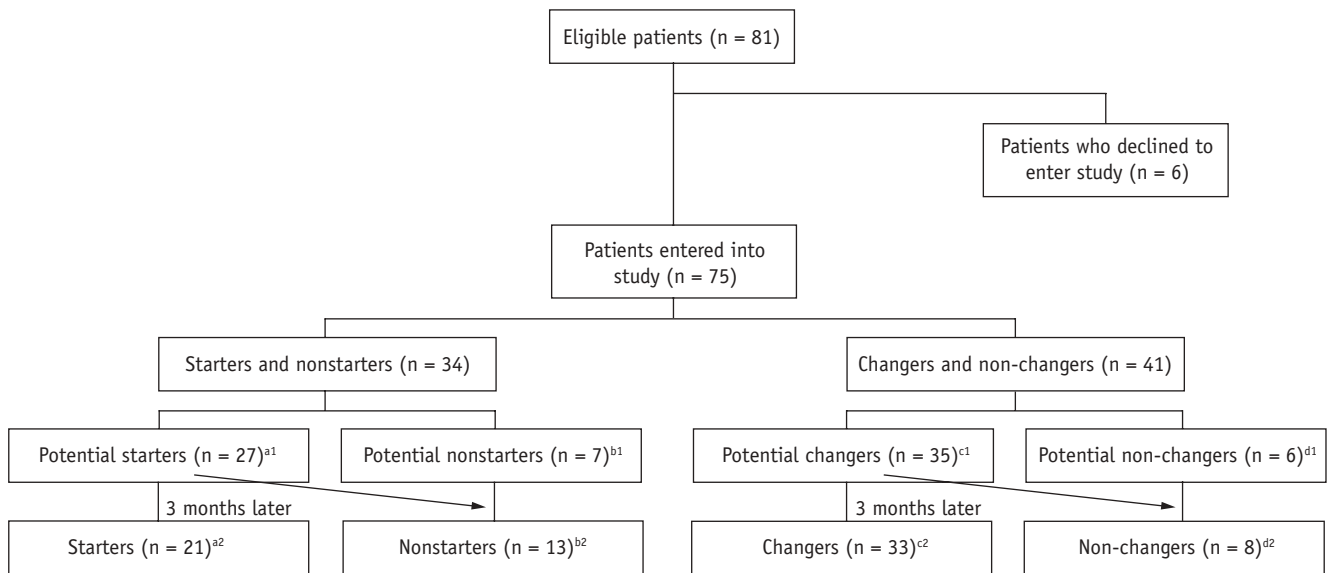


Figure 1. Four groups of patients: starters, nonstarters and changers, non-changers (^{a1}potential starters: 27 patients who decided to start therapy. ^{a2}Starters: 21 [78%] patients started therapy within 3 months. ^{b1}Potential non-starters: seven patients who decided not to start therapy. ^{b2}Nonstarters: 13 patients who did not start within 3 months. ^{c1}Potential changers: 35 patients who decided to change therapy. ^{c2}changers: 33 (94%) patients who changed within 3 months. ^{d1}Potential non-changers: six patients who decided not to change therapy. ^{d2}Non-changers: eight patients who did not change within 3 months).

would start therapy actually did not. Of the 41 patients in whom changing ART was considered, 35 (85%) patients indicated that they would change treatment and six indicated that they would not. Of these 35 patients, 33 (94%) finally changed ART. In agreement with his physician one patient decided in the study consultation to interrupt treatment. This was considered a treatment change. Eight patients did not change ART within 3 months. Following this, 21 of 75 patients were classified as starters, 13 as nonstarters, 33 as changers and eight as non-changers (Figure 1).

Patients' characteristics including mean HADS-Anxiety and Depression scores according to decision groups are shown in table 1. Nonstarters had a significantly higher depression score than starters ($p < 0.05$; mean difference in depression score: 5.63, 95% confidence interval: 1.78–9.48). Other group comparisons with respect to the HADS-Anxiety and HADS-Depression score did not reach statistical significance. Mental and physical quality of life scores as measured by the SF-8 yielded values between 38.0 and 48.8 but were not statistically significant (Table 1).

20 physicians and 12 nurses were study participants. Physicians were mostly men (60%) whereas nurses were mostly women (87%). Five physicians were between 20 and 30 years old, eight between 30 and 40 and seven over 40 years. Most nurses ($n = 10$) were over 40 years of age. In general, physicians and health-care workers were very experienced, i.e. physicians had a weighed average of 10 years experience and nurses 16 years, respectively. Experience in treating HIV-infected patients was also high (a weighed average of 7 years for physicians and 10 for nurses). Both,

physicians and nurses cared for study patients for a similar period of time, i.e. 2.0 years and 2.4 years on average, respectively. In the study, physicians and nurses spent an average of 36 and 9 minutes with a patient, respectively.

Reasons for Treatment Decisions

Of the 75 patients, 66 (88%; $n = 9$ missing) provided information about their reason for the treatment decision (Table 2). Seven patients did not provide exact information on the treatment decision, i.e. they reported immediately after the consultation that they wished to wait for another 3 months to decide (Table 2). The main reason to begin or change therapy (Table 2) was the sole recommendation of the physician (52% of starters and 61% of changers). All individuals except one indicated that they had received all the information needed to make a decision with respect to starting/changing ART. The physicians' recommendation was based on CD4 T-cell counts, viral load and other parameters such as adverse events and laboratory side effects, i.e. the main reason from the physician's perspective to start ART was a decrease in the patient's CD4 T-cell count (52%). The main reasons for physicians to change therapy were adverse events (41%).

Prediction of Starting or Changing Therapy

Of 34 HIV-infected patients without ART, 27 decided together with the physician that they would start therapy. Immediately after the consultation 26 patients predicted that they would start. Of these 26 patients, 21 actually started therapy (see Figure 1). Physicians and nurses predicted a

Table 1
Characteristics of HIV-infected individuals (n = 75) and main outcomes in questionnaires concerning anxiety, depression, and quality of life.

No. of patients	Starters 21	Nonstarters 13	Changers 33	Non-changers 8
Gender (% male)	19 (90%)	6 (46%)	27 (82%)	8 (100%)
Age at sampling time (mean, SD)	41 (28–60)	41 (28–65)	46 (26–76)	39 (31–48)
Transmission category				
Men having sex with men	11 (52%)	3 (23%)	21 (64%)	3 (38%)
Heterosexual contacts	5 (24%)	1 (8%)	6 (18%)	1 (12%)
Injecting drug users	5 (24%)	6 (46%)	4 (12%)	4 (50%)
Injecting drug users/sexual cont.	0 (0%)	2 (15%)	0 (0%)	0 (0%)
Unknown	0 (0%)	1 (8%)	2 (6%)	0 (0%)
HIV stage (CDC)				
A	8 (38%)	6 (46%)	9 (27.3%)	2 (25%)
B	8 (38%)	4 (31%)	13 (39.4%)	3 (37.5%)
C	5 (24%)	3 (23%)	11 (33.3%)	3 (37.5%)
HIV infection				
Duration of HIV infection at sampling time, years (mean, SD)	6.5 (± 5.2)	12.8 (± 4.6)	9.3 (± 4.3)	10.6 (± 5.0)
CD4 cell count (mean, median, SD; cells/μl)	380 (369 ± 212)	237 (235 ± 177)	442 (378 ± 289)	438 (391 ± 311)
Viral load, plasma (mean, median, SD; log ₁₀ c/ml)	5.05 (5.46 ± 0.83)	4.20 (4.06 ± 1.15)	2.69 (2.25 ± 1.42)	3.72 (3.93 ± 1.24)
Anxiety and depression				
HADS-Anxiety ^a	5.85	8.8	4.9	6.1
HADS-Depression ^b	3.2*	8.8*	3.6	4.4
Quality of life				
SF-8 MCS ^c (mean, SD)	4.6 (± 9.5)	3.8 (± 12.7)	47.9 (± 8.6)	47.6 (± 7.0)
SF-8 PCS ^d (mean, SD)	48.8 (± 12.0)	44.1 (± 9.5)	48.2 (± 10.1)	47.6 (± 11.2)

^a Hospital Anxiety and Depression Scale; score: no anxiety < 8, questionable 8–11, anxiety disorder > 11; ^b Hospital Anxiety and Depression Scale; score: no depression < 8, questionable 8–11, depressive disorder > 11; ^c mental component summary; average of United States' population = 50; ^d physical component summary; average of United States' population = 50; * p < 0.05

slightly higher rate of patients starting therapy, i.e. physicians and nurses thought that 27, and 30 patients, respectively, would start ART (Figure 2). Finally, 13 patients did not start therapy (Figure 2). Physicians predicted for seven patients that they would not start therapy. This prediction was two for nurses and patients, respectively. With respect to changing ART, the predicted treatment decisions were similar for the three study groups (Figure 2).

Shared Decision-Making

Patients were asked (n = 72, three missing) how they would describe the decision-making process that led to the treatment decision. This was done immediately after having seen the physician. As shown in figure 3, more than 50% of starters (n = 12, 57%), changers (n = 17, 53%), and non-changers (n = 4, 57%) perceived the treatment decision as shared “we decided together”. Nonstarters and non-changers more often stated “I decided mainly by myself.” Importantly, none of the patients reported that the physician decided alone. These results are in concordance

with the finding that patients preferred a shared approach. Starters as well as changers and non-changers preferred to decide together with their physician (47%, 65%, 88%, respectively). Furthermore, 71% of patients were very satisfied with the overall setting and content of the consultation and an additional 25% were satisfied. Only one patient answered being moderately satisfied. None of the patients reported being not or not at all satisfied.

Qualitative Aspects

Qualitative findings reflect the experiences of four women and eight men during the decision-making process. Two main aspects evolved, i.e. a) dealing with oneself and others and b) understanding and being understood.

Dealing with Oneself and Others. Patients experienced the entire decision process as highly distressing and even though a decision was made at the end, it was never perceived as final. They emphasized the time they needed for their inner dialogue and for discussions with others before making a

Table 2
Main reason for patients to start (not to start)/ change (not to change) a therapy^a.

No. of patients	Starters 21	Nonstarters 13	Changers 33	Non-changers 8
To start/change				
Physician told me	11 (52.0%)	3 (23.0%)	20 (61.0%)	2 (25.0%)
Decrease in CD4	1	1	1	0
Increase in VL	2	0	0	0
I feel bad	2	0	4	0
Other reason ^b	2	0	3	0
Not to start/change				
I feel healthy	1	1	0	1
I fear side effects	0	0	0	1
I fear toxic effects for the future (e.g. lipodystrophy)	0	1	0	0
Other reason ^c	0	0	0	1
To wait (another 3 months)				
I agree to start/change when next HIV parameters remain unfavorable	1	1	1	2 (25.0%)
I need time to think about the situation	1	0	0	1
Other reason	0	0	1	0
Missing	0	6 (46.0%)	3	0

^a Patients were allowed to choose only the most appropriate answer; ^b answers like: "I started/ changed ART because I know other HIV-infected individuals who started or changed therapy" or "a person in relationship recommended to start or change therapy" were not reported. Other reasons to start ART were "I want a baby" or "I want a non-detectable viral load to decrease the risk to infect my partner", other reasons to change were "I want a simplified therapy" and "I want a non-detectable viral load to decrease the risk to infect my partner"
^c Other possible answers like: "I will wait for a better therapy" or "the proposed therapy is too complicated" or "former HIV-parameters do not indicate that I have to start/change therapy" or "I would like a second opinion" or "I know other HIV-infected individuals, who had bad experiences with the medication" or "a person in a close relationship recommended not to start/change therapy" were not reported. One patient reported in the section "other reason": "I have to travel abroad for a certain time and therefore I will not change therapy." Percentages only given when > 20%.

decision. All interviewed patients worried about the side effects of a (new) treatment, especially the visible ones such as lipodystrophy. Patients balanced pros and cons of a treatment start or change very carefully. A 38-year-old man reported: "One goes back and forth and feels torn. Lipodystrophy affects my legs and this is disturbing but I can deal with it at the moment. It may be that a new medication helps – but one does not really know how it turns out."

Dialogues with others included reports about discussions with family members and friends. Patients told us that discussions with other HIV-infected people and health-care providers were most important. Information gathered through different media was also a key factor. Physicians and nurses were an important source of information, especially for persons with little illness experience. More experienced patients emphasized the different sources of information they used: "The information from friends and from the internet cannot be replaced by physicians, because the consultations are very limited and one is alone afterwards anyway."

Understanding and Being Understood. As a result of the diverse dialogues, patients were able to understand their

situation and felt understood by others. Discussions with health-care providers for instance helped to overcome worries and provided security. Some patients, however, did not feel really understood. Their inner dialogue, e.g. how they thought about the virus or how they felt related to the illness, was not concordant with the information they received from others. These patients explained that they could not understand the explanations of professionals and felt under pressure to take a decision they were not yet sure about. As a result, they expressed feelings of distress and anxiety.

Discussion

In this prospective study we explored the readiness to start or change ART in 75 HIV-infected individuals. We have shown that a) patients mainly complied with the decision made during the consultation and that physicians, nurses and to a lesser degree patients were too optimistic in predicting the start or change of ART, b) the main reasons to start or change ART were the physician's recommendation, and the reflection in dialogues that patients emphasized, c) patients mostly perceived the process as "shared decision-making", and d) depression was associated with a lower readiness to start or change therapy.

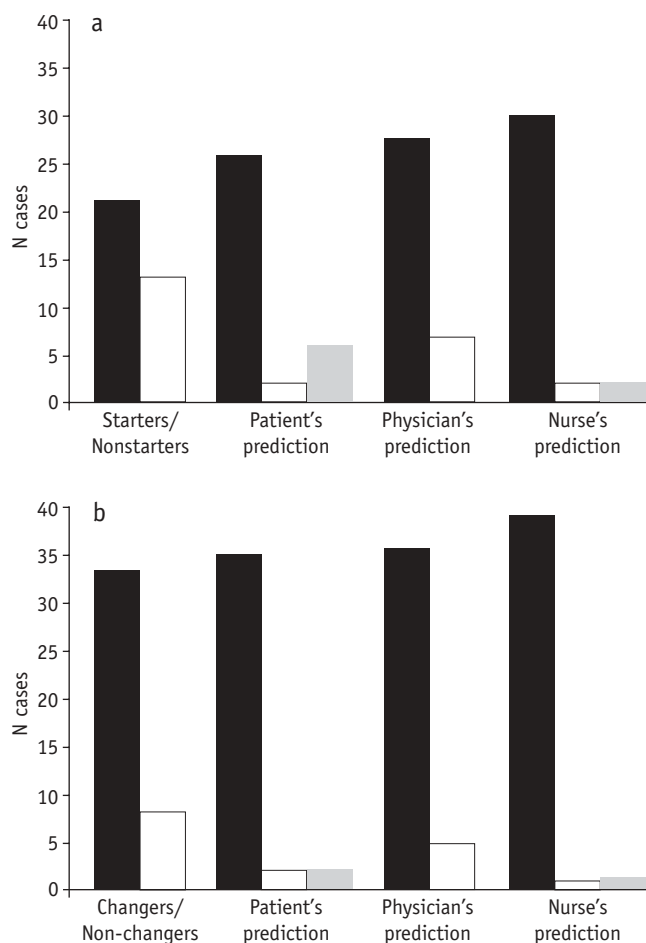


Figure 2. Prediction of starting (a) and changing (b) antiretroviral therapy compared to those who really started or changed therapy. Figure 2a: black bars depict “start”, white bars “no start”, grey bars answers such as: “I do not know” or “I/ she/ he will start soon, i.e. within the next 3 months”. Figure 2b: black bars depict “change”, white bars “no change”, and grey bars answers such as: “I do not know” or “I/she/he will start soon, i.e. within the next 3 months.”

Patients mainly complied with the decision made during the consultation. Of 27 patients who decided to start therapy, 78% actually started ART. Of 35 patients who decided to change therapy, 94% actually did. These results show a high concordance between planned and real treatment procedures. This indicates that both patients and physicians agreed on the treatment decision to a large extent and that the physician-patient communication was “successful”. Nevertheless, physicians and nurses were too optimistic in predicting the start or change of ART. Recent studies indicate that the providers’ prediction and perception of readiness and adherence to therapy may play an important role in prescribing ART. *Bogart et al.* [14, 15] showed that most physicians treating HIV-infected individuals weighed patient’s prior history of poor adherence and socio-demographic factors against initiating ART. *McNaghten et al.* [16] found that ART prescription differs

by gender, race, exposure mode, alcoholism, and provider type. Earlier, we demonstrated that the physician’s perception of a patient not complying with treatment was the main reason for not prescribing ART [17]. However, physicians’ perception may not be a reliable basis for treatment decisions because of their questionable prediction of patients’ adherence [18–22].

The main reason to start or change antiretroviral therapy was the physician’s recommendation. This was the case in 52% of the starter group and 61% of the changer group. As we asked patients to indicate only the most important reason, this probably led to an underestimation of reasons that were not dominant. However, this may have allowed a better discrimination for reasons that were more influential in deriving a decision. The notion that the physician is a very important partner for judging the appropriateness of treatment decisions is supported by a recent study. *Meystre et al.* [23] reported that 42% of a cohort of 830 patients expressed that the physician’s advice was one of the main reasons to accept ART. The qualitative categories of “dealing with oneself and others” shed light on the patients’ expertise related to daily life and personal illness management. Also, the category of “understanding and being understood” indicates some dissatisfaction with the decision-making process and reveals how distressing such a situation might be. It also shows that patients’ treatment decisions are dependent upon patients’ perceptions of understanding the situation and feeling understood by healthcare providers and support persons [24].

In our study almost all (97%) HIV-infected individuals reported that they had received all the information needed to decide whether to start or change ART. HIV-infected individuals mostly perceived the process as “shared decision-making.” This confirms previous findings of *Marelich*

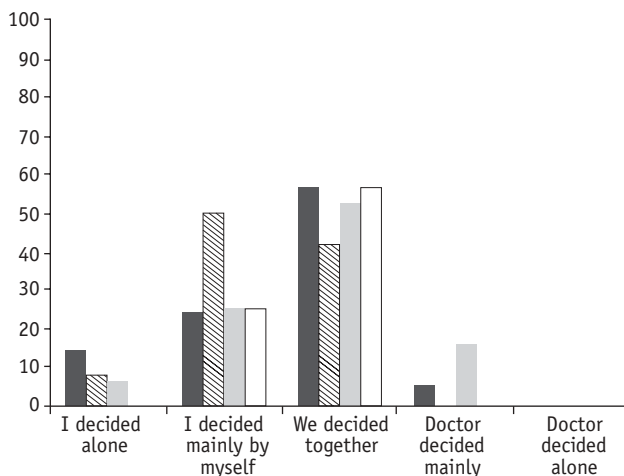


Figure 3. HIV-infected individuals’ judgement about involvement in the treatment decision. Black bars depict “starters”, bars with diagonals “nonstarters”, grey bars “changers”, and white bars “non-changers.”

et al. [25] who found that HIV-infected individuals were generally actively involved in the decision-making process. In this latter study a passive attitude of the patient was only found immediately after HIV infection was diagnosed. An active role was also found by others [26]. In addition, our study shows that physicians and nurses are important partners and therefore strongly influence the readiness of HIV-infected patients for therapy. This is also supported by our finding that the physician's recommendation was the main reason to start or change ART, stressing the importance of the provider-patient communication and relationship. Along these lines, 71% of patients were "very satisfied" with the decision-making process. It may be that these encouraging results are partly based on the great experience of physicians and nurses. In addition, the more critical qualitative data emphasize the importance of communication skills of physicians and nurses with patients [27].

A higher depression score was associated with lower readiness to start antiretroviral therapy. Despite the low number of patients this result was significant. A meta-analysis of ten studies, including a total of 2,596 persons, by Ciesla et al. [28] provides strong evidence that HIV infection is associated with greater risk for major depressive disorders. Similarly, we found high scores for anxiety and depression in a large survey within the Swiss HIV Cohort Study even in asymptomatic patients with good surrogate markers [29]. Consequently, depression has to be considered when starting or changing ART.

Our study has limitations. First, the number of patients included in this study is rather low, e.g. gender differences could not be analyzed. However, the design to investigate patients, physicians, and nurses was to analyze prospectively detailed quantitative as well as qualitative aspects. Hence, our results may give important insights for decision-making with respect to ART. Second, the follow-up period for evaluating whether the treatment decision was actually realized was only 3 months. A longer period of time may have affected the number of patients in the different decision groups as, e.g. some additional patients may have started therapy. However, we sought to determine whether the decision taken during consultation was actually realized within a short period of time, because otherwise the decision-making process may have been influenced by new aspects. Finally, the decision-making process may have been influenced by the communication skills of health professionals as well as by difficulties of health professionals in assessing the patient's readiness. However, most physicians and nurses had substantial professional experience in treating HIV-infected patients and their communication skills should be reflected by their level of experience. Furthermore, the results were very similar across the four included study sites (data not shown) and overall patient satisfaction was high arguing against an unbalanced influence of health-care providers. Nevertheless, we cannot exclude a selection bias of our study population. It is possible that the positive perception of the decision-making process and the

high satisfaction rate were partly due to a selection of patients who were a priori satisfied with the involved centers. Yet, this reflects real conditions.

The recommendation of a doctor seems very important; however, shared decision-making turned out to be a crucial support for all the involved persons. Also, our qualitative data indicate that treatment decisions are a dynamic process strongly linked to personal experiences. As therapeutic options become more and more individualized, further qualitative research is needed to improve the understanding of the treatment decision process.

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