

Involvement of people living with HIV in treatment-related decisions

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1. Background

The steady improvement of antiretroviral therapy during the past decades has had a major impact on the life expectancy and the quality of life of people living with HIV, and therefore also on the relationship between patients and their physicians. What HIV therapy was at the beginning of the epidemic, namely a weak treatment for the life threatening complications of AIDS (and basically an end-of-life palliative remedy), has over time become sustained lifelong care. The good relationship between patients and physicians represents the cornerstone of optimal long-term therapy. Shared decision-making between patients and physicians is a crucial prerequisite for the success of this therapeutic approach. Several Austrian patient organizations, together with MSD Austria, developed an online survey (the so-called "PAB-test") aimed at assessing how people living with HIV perceive the level of care in Austria. This survey included several modules dedicated to the evaluation of the patient-physician relationship.

2. Materials and Methods

Several Austrian patient organizations developed an online survey together with MSD Austria, aimed at assessing how people living with HIV perceive the level of care in Austria. The survey was available in a paper version and online, in German and English. Collection of data took place between December 2013 and July 2014. People living with HIV were informed about the survey and asked to participate by patient organizations, in hospitals and outpatient care institutions.

This survey included several modules, of which session 2 was dedicated to the evaluation of the patient-physician relationship and to assess to what extent people living with HIV feel involved in treatment related decisions. The results of this topic are presented in this poster.

3. Results

A total of 303 subjects completed the questionnaire. 208 participants were male, 65 female, 4 transgender (26 missing). 133 persons described their sexual orientation as homosexual, 106 as heterosexual, and 20 as bisexual (34 participants didn't answer this question). Most participants (43.6%) were in the age-group of 36–50 years.

In 30.6% of the participants, HIV was diagnosed more than 16 years ago, in 21.1% 9–15 years ago, in 26.8% 4–8 years ago, in 21.8% less than 4 years ago. The highest number of respondents (29.3%) were on antiretroviral treatment for 4–8 years, 27.6% less than 4 years, 21.5% for 9–15 years, 14.8% more than 15 years, 6.7% were naïve to ART. 29.4% of the participants who received antiretroviral therapy were on first line ART, in 70.6% ART had already been switched at least once.

Being asked the question "How much do you feel involved in the decisions related to your HIV treatment?" 44% answered to feel "totally" involved in their therapy, 40% "strongly involved", 12% "fairly involved", 3% "poorly involved" and 1% "not involved at all" in their therapy. The proportion of subjects who felt "totally" involved in the therapy was equally distributed between sexes, sexual orientation, age group, level of education, and between patients treated predominantly in intramural or extramural medical care facilities. To the question "How much would you like to be involved in the decisions related to your HIV treatment, compared to now?" 23.9% of the participants answered they would like to be more involved in treatment-related decisions.

The participants were asked to describe how they felt concerning the following statements, if applicable: "My active involvement in the discussion about the treatment choice at the time when I got my first HIV treatment was" and "My active involvement in the discussion about the treatment choice at the time when I got to change HIV treatment was" (1: weak/2: moderate/3: strong/4: very strong)

Concerning the involvement in the choice of first ART, the result was a mean value of 2.42 (SD: 1.04). Concerning the involvement in the first switch of ART, the result was a mean value of 2.78 (SD: 0.93) (Table 1).

The question "How important are the following factors for you when it comes to decide your HIV treatment? Please rate the importance of each factor from 1 to 6, depending on how important the factors are for you, where 1 means absolutely important and 6 means absolutely NOT important." showed that the most important factor for people living with HIV concerning the choice of their antiretroviral therapy (ART) was a low amount of long-term ART-related side-effects, followed by a low amount of short-term ART-related side-effects, and by once-daily drug intake (Figure 1).

	My active involvement in the discussion about the treatment choice at the time when I got my first HIV treatment (N = 250; 182 men, 59 women)	My active involvement in the discussion about the treatment choice at the time when I got to change HIV treatment (N = 217; 163 men, 46 women)
total	2.42 (1.04)	2.78 (0.93)
Sex: male	2.47 (1.04)	2.80 (0.94)
female	2.22 (0.97)	2.70 (0.89)

Table 1: Patient's involvement in therapy decisions ranked in a scale from 1 (least) to 4 (best). Mean values (SD)

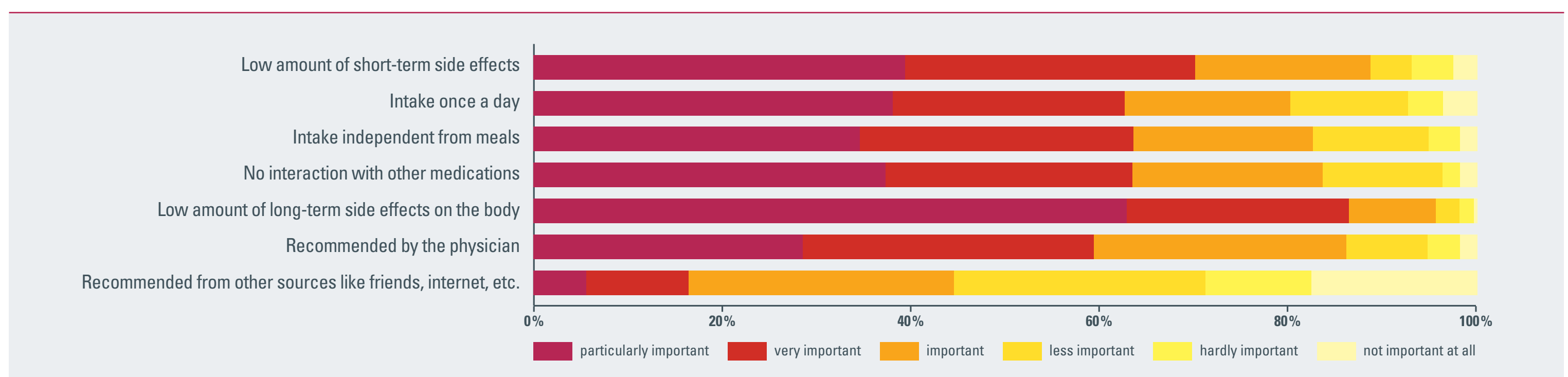


Figure 1: Importance of therapy-related factors for choice of ART (proportion of participants)

Conclusions

The results show that the majority of people living with HIV in Austria feel involved in therapy-related decisions. This proportion is equally distributed through patient groups with different socio-demographic or socio-economic characteristics or level of medical care access. Especially concerning the choice of first line ART the results show room for improvement. According to the survey, the most important factor for people living with HIV concerning the choice of their ART is to avoid long-term side effects.

