Health literacy, source of information and impact on adherence to therapy in people living with HIV

Thomas Ernst Dorner[1], Kathrin Schulte-Hermann[2], Matteo Zanini[2], Wiltrut Stefanek[3], Birgit Leichsenring[4]

[1] Institute for Social Medicine, Centre of Public Health, Medical University Vienna, [2] MSD Austria, [3] PULSHIV, [4] Aids Hilfe Wien

1. Background

Adequate information and health literacy (HL) has a high impact on patients´ understanding of the causes and consequences of many chronic diseases, including HIV, and is a crucial prerequisite to ensure adherence to therapy regimens. Several Austrian patient organizations, together with MSD Austria, have 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 includes modules dedicated to the evaluation of HL in people living with HIV, and to evaluating the impact of HL on adherence to therapy.

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. One objective was to assess health literacy (HL) in people living with HIV, and to evaluate the impact of HL on therapy adherence. The results of this topic are presented in this poster.

HL was assessed by means of seven, self-rated, questions on the comprehension of HIV related information, showing a high degree of reliability (Cronbach`s alpha = 0.876). Low health literacy was defined as reaching a score below the median of 20 points in the related indicator. The chi2-test was used to test for significance.

Proportion of patients who …	High health literacy	Low health literacy	P
…missed appointments	14.4 %	30.0 %	0.037
…interupted therapy without consulting a physician	9.8 %	22.4 %	0.006
…reported having forgotten medication intake	39.1 %	33.1 %	0.305

Table 1: Proportion of patients with high vs. Low health literacy who reported deficits in therapy adherence

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.

Women, slightly more often, had a lower HL than men (57.1 % vs. 44.7 %, P=0.335). Heterosexual participants had, more often, a lower HL compared to homosexual ones (58.3 % vs. 38.1 %, P=0.007). Health literacy slightly increased with age (not significant). Increased education levels correlated with a higher HL (66.7 %, 46.2 %, and 38.9 % of persons with primary, secondary, and tertiary education, respectively, showed low HL P=0.037). The number of missed appointments with the HIV physician was significantly higher in low HL people, who were also more prone to interrupting therapy without consulting a physician. Low HL population, however, did not report having forgotten medication intake more often than population with high HL (Table 1). The most important source of information was the treating physician, followed by NGOs/patient organizations and the internet (Figure 1).
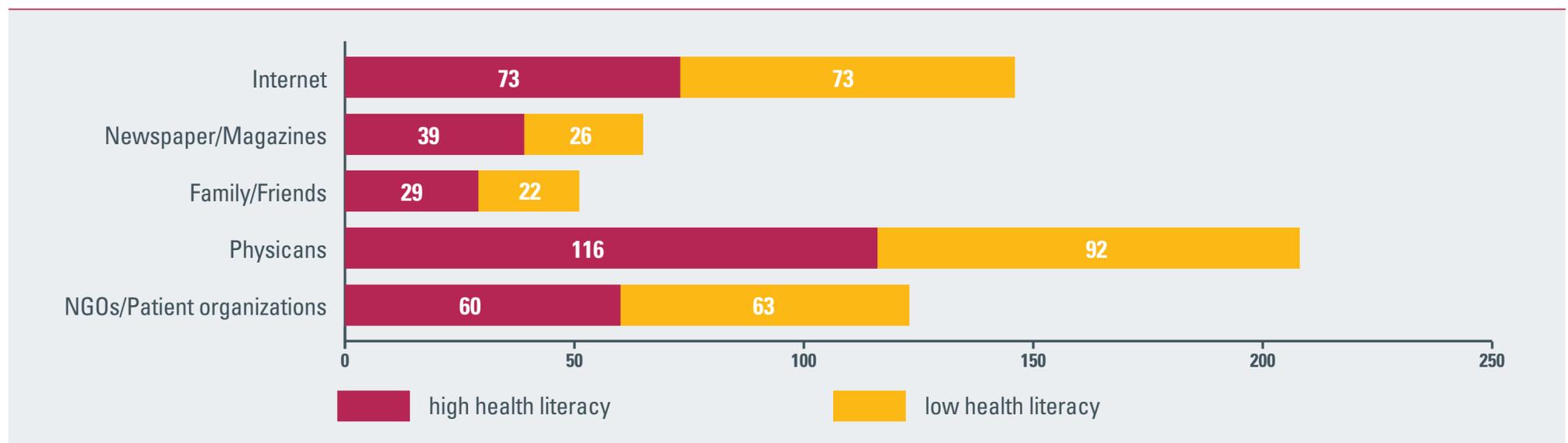

Figure 1: Sources of information for people living with HIV with high and low HL (absolute numbers of respondents)

Conclusions

There are significant differences in HL between the different sub groups within the HIV community. Low HL is significantly associated with a higher frequency of missed doctor appointments and interruptions of treatment, but does not impact adherence to therapy (self-reported). The identified information providers (medical doctors, NGOs/patient organizations) should be encouraged to contribute towards increasing HL in HIV patients.