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## AIDS Care

Publication details, including instructions for authors and subscription information:

<http://www.informaworld.com/smpp/title-content=t713403300>

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Online Publication Date: 01 March 2009

**To cite this Article** Rogowska-Szadkowska, D., Chlabicz, S., Oltarzewska, M. A. and Sawicka-Powierza, J. (2009) 'Which factors hinder the decision of Polish HIV-positive patients to take up antiretroviral therapy?', *AIDS Care*, 21:3, 280 — 283

**To link to this Article:** DOI: 10.1080/09540120802241871

**URL:** <http://dx.doi.org/10.1080/09540120802241871>

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## Which factors hinder the decision of Polish HIV-positive patients to take up antiretroviral therapy?

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*(Received 5 December 2007; final version received 29 May 2008)*

The implementation of highly active antiretroviral therapy (HAART) in 1996 has significantly reduced mortality and morbidity for HIV-positive patients worldwide. However not all eligible persons start HAART. To identify reasons for therapy refusal by HIV-positive persons we performed a questionnaire study. The investigation was conducted among 321 HIV-positive individuals and focused on the decision to take up antiretroviral treatment. Out of 71 untreated patients, 34 (47.9%) admitted that in their case the therapy was not indicated, whereas 20 (28.3%) were afraid of potential side effects that might change their appearance, e.g. face lipoatrophy. Only the treated patients had been prepared to take up therapy, although 17 patients (6.0%) had not received any explanation of the therapy principles, aims or necessity to comply with medication regime. The therapy is generally not discussed with the patients for whom it is not currently indicated, which may contribute to the fixation of fears and prejudices. Doctors who treat HIV-positive patients should be aware of the prejudices and fears their patients have towards antiretroviral therapy in order to react properly and by means of the available antiretroviral drugs help prolong life and improve its quality.

**Keywords:** HIV; antiretroviral agents; prejudice; fear

### Introduction

In Poland, the first 11 cases of HIV infection were reported in 1985 (Rosińska, 2006), the first case of AIDS identified one year later (Szata, 1990). At the beginning HIV infection was frequently diagnosed in its late stages and the patients died within a few months after AIDS had been diagnosed (Szata, 1991).

The implementation of highly active antiretroviral therapy (HAART) in 1996 has significantly reduced mortality and morbidity for HIV-positive patients worldwide (Mocroft et al., 2003; Palella et al., 1998), also in Poland (Podlasiński et al., 2006). Somewhat later importance of adherence to treatment for therapeutic efficacy was demonstrated (Paterson et al., 2000) and reports on late adverse effects of antiretroviral medications began to appear (Montessori, Press, Harris, Akagi, & Montaner, 2004).

In Poland, antiretroviral therapy is provided only by Reference Centres that are usually attached to University Hospital Departments of Infectious Diseases. Although all HIV-positive patients are eligible to receive free medication, not all decide to start therapy. This problem does not only concern Polish patients but has been also reported by authors from other countries (Bassetti et al., 1999; Gold, Hinchey, & Batrouney, 2000; Maisels, Steinberg, & Tobias, 2001).

As the reasons for therapy refusal by HIV-positive Polish patients had not been investigated we decided to elucidate what factored into the decision not to take medications, as well as to obtain some knowledge of patients' preparation to therapy and of the doctor–patient relationship.

### Material and methods

For the needs of the study, initially designed to compare the situation of HIV-positive subjects before and after the diagnosis, we designed a questionnaire containing 75 questions. Respondents were asked to provide information about their personal situation (marital status, education, source of income, place of living, etc.) one year before learning they were HIV-positive, ways the message about HIV infection was delivered, current personal situation, antiretroviral treatment or the reasons for declining a treatment offer. The questionnaire forms were distributed among HIV-positive patients at their meetings (at the Polish National Meeting for People Living with HIV in June 2004 and at “Salon of Acceptance” in Warsaw, a monthly meeting of HIV-positive persons), or were sent to patients of nearly all the HIV/AIDS Reference Centres. The respondents were asked to complete them at home and send them

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back to the person conducting the research. The questionnaires were distributed in the period of June 2004–May 2005.

Statistics were analysed with SPSS software, version 11,5 Pl.

### Study results

The response was obtained from 321 subjects out of 500 questionnaires prepared (64.2%). Among 321 subjects there were 201 men (62.6%) and 117 women (36.4%). Three subjects (0.9%) did not give information about gender. At the time of completion, the respondents were aged  $35.29 \pm 7.99$  years on average.

Answering the question about risk factors for HIV infection, the respondents frequently gave more than one answer. In more than half of the patients – 188 (59.2%) the main risk factor was injection drugs use, in 88 (27.4%) – heterosexual contacts and in 60 men (19.3%) – homosexual contacts. The infection through blood transfusion was suggested by three persons (0.9%). Three patients (0.9%) did not know how they had been infected.

Most respondents (248; 77.3%) were on HAART, 71 (22.1%) were not treated, two persons (0.6%) failed to answer.

Reasons behind decisions not to take up antiretroviral therapy have been shown in Table 1.

The respondents were also asked if they had been prepared to the start of antiretroviral therapy by a treating doctor. Responses were provided by 232

Table 1. Reasons for not taking up antiretroviral therapy as given by the study patients.

Reasons for not taking up antiretroviral therapy ( <i>n</i> = 71)	No. of subjects (%)
Lack of indications for therapy (high CD4 cell count, low viral load)	34 (47.9)
Fear of side effects due to antiretroviral medications	20 (28.3)
Treatment of other diseases, e.g. interferon therapy for HCV infection	4 (5.6)
Long distance (70–100 km) to a doctor	4 (5.6)
Addiction to injection drugs	2 (2.8)
Expecting new more effective medications with fewer side effects	2 (2.8)
Fear that medication intake will interfere with everyday activities	2 (2.8)
Alcohol addiction	2 (2.8)
Withdrawal from medications after a short period of intake and poor tolerance	1 (1.4)

subjects. Only the treated patients had been prepared to take up therapy, although 17 patients (6%) had not received any explanation of the therapy principles, aims or necessity to comply with medication regime. The therapy was not discussed with the patients for whom it was not currently indicated. Two hundred and sixty-seven participating patients provided assessment of the quality of preparation to antiretroviral therapy using the scale from 1 (no preparation) to 5 (very good preparation). The mean grade was 4.1.

### Discussion

This study has demonstrated a significant degree of prejudice regarding antiretroviral therapy among asymptomatic patients, which may contribute to the decision of HAART refusal.

The current findings are not fully representative of all HIV-positive patients in Poland. The study was conducted among HIV patients who cope well with the awareness of being infected – they participate in patients' meetings and willingly cooperate with their doctor in charge. It is possible that many HIV-positive patients in Poland, especially injection drug users, live in isolation and are not under medical care.

Most of the untreated study participants claimed that in their case antiretroviral therapy was not indicated due to high CD4 cell count and low viral load. However some of them admitted having check-up examinations done more seldom than once a year. Doubts associated with the necessity of being on therapy were related to the lack of HIV symptoms, good general health condition and the feeling that HIV should have a natural course. Similar findings have been reported elsewhere (Cooper et al., 2002; Horne, Cooper, Gellaitry, Date, & Fisher, 2007).

Almost 1/3 of non-treated study participants refused antiretroviral therapy because of fear of side effects. They were mostly afraid of lipodystrophy, especially face lipoatrophy. This is in agreement with observations from many other countries (Alfonso, Bernbach, Geller, & Montaner, 2006; Bassetti et al., 1999; Gellaitry et al., 2005; Gold et al., 2000; Green & Smith, 2004; Maisels et al., 2001). In Poland, in contrast to, for example, Great Britain (Gazzard on behalf of BHIVA Writing Committee, 2006) there are no guidelines concerning ways of improvement of the appearance of HIV-positive patients. For some patients long distance to a HIV specialist was the main reason for not starting HAART, because in case of side effects, their family doctors would not be able

to help. Those living in small towns additionally feared that the information of their disease recorded in patients' files would be accessible to other workers of a health centre, and thus to other town inhabitants. However, HIV-positive patients have great trust in doctors and staff working in Reference Centres, as no cases of confidentiality violation have been reported from these places (data not shown). Problems with using local general practitioner services do not concern only Polish patients but has been also reported by authors from other countries (Petchey, Fransworth, & Williams, 2000).

Drug or alcohol addicts tend to refuse HAART therapy more frequently (Ding et al., 2005). Opiate and alcohol addicts in this study were afraid of interactions between antiretroviral medications and narcotics or alcohol, some complained that doctors did not offer them treatment although HAART was medically indicated. In Poland, especially in small towns, there is little or no access to methadone therapy or alcohol detoxification treatment.

Most of our respondents who were not on treatment did not answer the question concerning preparation to HAART by their charge doctor. It can be thus assumed that doctors do not discuss the therapy with asymptomatic patients, which may lead to fixation of prejudices and wrong opinions regarding HAART. Some patients on antiretroviral treatment had not been prepared to it, which may affect their later adherence.

Doctors treating HIV-positive patients should be aware of fears and prejudices against HAART in order to properly react and help patients take the chance to prolong life and improve its quality.

### Acknowledgements

The authors wish to thank doctors from the following Reference Centres (in alphabetic order) for their assistance in data collection: Białystok, Bydgoszcz, Chorzów, Kraków, Łódź, Poznań, Szczecin, Warszawa and Wrocław.

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