

Reasons of loss to follow-up among people living with HIV. Summary of in-depth interviews.

Kristi Rüütel, Liis Lemsalu
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Background

The objective of this study was to determine the reasons why people living with HIV (PLHIV) discontinue antiretroviral therapy (ART) and are lost to follow-up, and based on that propose ways in which to improve health care and social welfare services.

Methodology

17 adult patients, who spoke Russian, were interviewed. Participants were recruited by infectious diseases specialists from Lääne-Tallinna Keskhaigla (n = 5) and Ida-Viru Keskhaigla (n = 12).

Results

PLHIV are generally satisfied with infectious disease care provided to them. The healthcare services are seen as relatively easily accessible and the attitude of healthcare workers towards PLHIV are perceived to be good. Regarding doctor-patient relationship, the most common problem mentioned was incompatible personalities between the doctor and the patient. Long waiting-lists in Ida-Viru County were highlighted as a significant issue. Some study participants also mentioned visit fees (five euro fee per three months) and the need for frequent visits to the infectious diseases clinic to pick up their medications.

All participants had received ART at some point and some were on ART at the time of the study. Often mentioned reasons for discontinuation or refusal of ART were feeling well and desire for their immune system to fight the virus on its own. Nearly everyone mentioned side effects of ART and in several cases those side effects were the main reason for discontinuation of treatment or changing medications. Other reasons given for discontinuation of treatment or infrequent visits to infectious diseases doctor included being away from home, consumption of alcohol and use of illegal drugs, forgetting and laziness.

Conclusions

Since ART is a life-long treatment, patients need constant support both from medical personnel and close ones. The availability and quality of HIV-related information and counselling for both patients and their close ones needs to be improved. One key aspect of improving the quality and ensuring the continuity of services is personal approach to patients and the flexibility of the health care system in order to find a suitable solution for each individual.

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