Illness Perception of Young Patients with HIV Infection

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Abstract

The infection with the Human Immunodeficiency Virus (HIV) has become a chronic disease due to effective antiretroviral therapy (ARVT) that can provide complete and sustained viral suppression. The perception of HIV diagnosis has changed, from "condemnation to death" to long-term survival and life expectancy similar to the general population. The HIV epidemic in Romania is predominant in cases diagnosed in infants born in 1987-1991, with nosocomially transmission during the first years of life. The aim of our work is to assess the perceptions of the course of the disease among persons living with HIV and the influence of factors such as demographic factors, time of HIV diagnostic, immunity and viral suppression under the ARVT. The brief version of Illness Perception Questionnaire (IPQ) for assessment of cognitive and emotional representations of illness, comprehensibility and an inventory questionnaire scoring symptoms were applied by a cross-sectional study among patients in the Daily Clinic for *HIV Evaluation and Treatment* from the Infectious Diseases Hospital in Galati, Romania. The most frequent age of patients with HIV from the clinic is under 35 years and they have good knowledge about their disease. The ARVT is efficiently controlling the clinical and viral markers of disease. However, half of the respondents are emotionally affected by living with HIV. The negative perception of HIV infection is more severe among females and people with viral failure treatment, although various and even contradictory perceptions were found, according to the answers collected. The adherence support of medical teams requires personalized management of HIV patients.

Keywords: HIV, illness perception, questionnaire

Introduction

Over 35 years have passed since the emergence of the infection with human immunodeficiency virus (HIV) is spreading into a pandemic. Many impressive scientific discoveries from the last years were accomplished to better understand the pathology of acquired immunodeficiency syndrome (AIDS) and to use efficient antiretroviral drugs, improving the life expectancy of HIV infected patients [1]. Impressive AIDS is arguably the greatest global healthcare challenge facing our generation. Although there is not a cure and an effective vaccine until now, a comprehensive treatment program can improve the quality of life for people living with HIV (PLWH) [2].

The effective antiretroviral therapy (ARVT) can provide complete and sustained viral suppression, very good control of the symptoms, and almost zero epidemiological transmission. In other words, HIV infection has become a manageable chronic disease. The perception of HIV diagnosis has changed, from "condemnation to death" toward long-term survival disease, with life

expectancy similar to the general population [3]. However, both for patients and the general population, discrimination is the main perception related to HIV infection [4].

The HIV epidemic in Romania is distinctive owing to the high number of people born during 1987-1991, nosocomially infected during their early childhood. Presently, over one third of Romanian PLWH were diagnosed near three decades ago [5]. Furthermore, people from the same cohort of age newly diagnosed with HIV infection are related to other transmission ways, mostly by heterosexual contact, sex between men or intravenous drug use. Perinatal transmission was evidenced in a minority of cases.

The aim of our study is to assess the perceptions of the disease among young persons living with HIV and the influence of demographic factors, the assumed way of HIV transmission, the length of HIV diagnostic, the immunity and viral suppression under the ARVT.

Methods

We have conducted a cross-sectional study among 115 patients with HIV, presented for routine monitorization and antiretroviral treatment to the daily clinic of the Infectious Diseases Hospital in Galati, Romania. The including criteria were: age between 20 and 35 years, on current antiretroviral treatment, time of HIV diagnostic over 2 years, and written informed consent for the study questionnaire. We have excluded the severely ill patients with opportunistic or intercurrent associated diseases, depressive patients with score over 13 by depression Back-II inventory [6], such as patients with neurocognitive impairment, according to screening test by International HIV Dementia Scale Score less than 8/12 [7].

We used the brief version of "Illness Perception Questionnaire" (IPQ), with a causal open-ended response item and eight items rated a 0-to 10 response scale, assessing cognitive illness representations (item 1 - consequences, item 2 - timeline, item 3 - personal control, item 4 - treatment control, item 5 - identity), emotional representations (item 6 - concern, item 8 - emotions) and comprehensibility (item 7). The score was computed as a sum of the scores for items 1, 2, 5, 6, 8 and of reverse score items 3, 4, and 7. A higher score reflects a more negative perception of the illness [8].

At the end of IPQ, the patients expressed their opinion related to the cause of their HIV disease, by choosing one of the following items: stress, heredity, a virus or other microbe, food, bad luck, medical negligence, pollution, own behavior, negative thoughts, familial problems, overwork, emotional state, age, alcohol, smoking, an accident, their personality or immunity [9]. The identity score (IS) inventoried 14 symptoms, each of them rated with 1 point [10]. An additional questionnaire collected the demographic data, the risk factors for HIV transmission, the length of HIV diagnostic, current CD4 Lymphocytes count and the status detectable or undetectable of ARN-HIV viral load. Data analysis used Statistical Software Package XL-Stat. Descriptive statistics, correlation analysis including Pearson, Spearman and Kendall correlation coefficients and simple linear regression were applied.

Results

There were 115 eligible patients evaluated by IPQ. They were selected from 351 PLWH monitored in the Infectious Diseases Clinic in Galati, during March 2018. The average age was 28±1.58 years [Min 22; Max 34], 48.7% were female, 43.3% lived in rural areas. The average time of formal education was 8.2±3.69 years. A percent of 53% were married or had a stable partner, and 44.3% are raising one or more children. There were 41.3% smokers, while 28.6% PLWH admitted alcohol use [Table I].

The experience of HIV diagnostic was variable, since 2 to 28 years, with an average of 15.6±6.6. This is related to ARVT experience of average 7±2.3 drugs combination, but with average length of 7 ±4 years for the current ARVT [Table II].

The transmission way was mainly nosocomial (75%), followed by sexual (10%) and perinatal (5%), while for 10% it was unknown [Figure 1].

The median of the current immunity was 523.5/mm3 of LCD4, and 70.4% (81/115) patients dropped under virologic target with undetectable viral load.

Table I: Demographic characteristics

	n	**%**	**p**	**CI 0,95**
Gender - Female	56	48.7%	0.77	0.40; 0.60
Living area - Rural	50	43.3%	0.161	0.34; 0.52
Married or couple	61	53%	0.513	0.43; 0.62
Children	51	44.3%	0.22	0.35; 0.53
Smoking	59	41.3 %	0.77	0.39; 0.57
Alcohol use	33	28.6%	<0.001	0.20; 0.37

Table II: Characteristics of HIV

	Average	**SD**	**Median**	**Min**	**Max**
Time of HIV diagnostic	15.6	±6.6	16	2	28
Treatment "Experience" (no. of ARVT combinations)	7	±2.3	6	1	13
Duration of current ARVT (years)	7	±4	7	1	16
Current immunity (CD4 Lymphocyte count/mm^3)	533	±282	523.5	25	1390

We asked the patients to identify the cause of the disease among the following items: stress, heredity, a virus or other microbe, food, bad luck, medical negligence, pollution, own behavior, negative thoughts, familial problems, over work, emotional state, age, alcohol, smoking, an accident, their personality or immunity. Medical negligence was considered the cause of their HV infection in 67%, bad luck in 9%, a virus in 7%, own behavior in 5% and 12% answered "I don't know" [Figure 2].

The inventory of the symptoms that are attributable to HIV was identified by the second item. Headache was found most frequently (30%). Near a quarter of patients complained of sore eyes (25.66%), stiff joints (24.78%) and fatigue (24.78%). Other symptoms were: dizziness (21.73%), sleep difficulties (21.4%), loss of strength (21.24%), upset stomach (19.47%), pain (15.9%), breathlessness (15%), nausea (11.5%), sore throat (10.6%), weight loss (9.73%) and wheeziness (4.4%) [Table III]. Based on the sum of identified symptoms for each patient, the average identity score (IS) was 2.55±2.71. Remarkably, almost half of the patients (46.9%; 54/115) did not complain of any symptom.

Table III: Inventory of experienced symptoms related to HIV

	Experienced symptoms related to HIV	**Yes**	**No**	**Frequency**
1	Pain	18	95	15.9%
2	Sore Throat	12	101	10.6%
3	Nausea	13	100	11.5%
4	Breathlessness	17	96	15%
5	Weight Loss	11	102	9.73%
6	***Fatigue***	***28***	***85***	***24.78%***
7	***Stiff Joints***	***28***	***85***	***24.78%***
8	Wheeziness	5	108	4.4%
9	***Sore Eyes***	***29***	***84***	***25.66%***
10	***Headaches***	***34***	***79***	***30%***
11	Upset Stomach	22	91	19.47%
12	Sleep Difficulties	24	89	21.24%
13	Dizziness	25	89	21.73%
14	Loss of Strength	24	89	21.24%

On a scale from 0 to 10, the answers to the brief IPQ were scored and analysed for each item [Table IV].

Table IV: Summary of IPQ answers among HIV patients

	Question	**Dimension of illness perception**	**μ***	**№ Score 0**	**№ Score 10**	**Av. points**
1	How much does your illness affect your life?	Consequences	5	0	30	4.6
2	How long do you think your illness will continue?	Timeline	10	3	88	7.2
3	How much control do you feel you have over your illness?	Personal control	10	0	62	1.5
4	How much do you think your treatment can help your illness?	Treatment control	10	3	10	0.8
5	What are the illness symptoms you experience?	"Identity"	0	59	13	2.4
6	**How concerned are you about your illness?**	Concern	1	50	29	6
7	How well do you feel you understand your illness?	**Coherence**	10	0	58	2.2
8	How much does your illness affect you	Emotional	4	42	21	4.1

	emotionally?	representation				

μ*: Median score

The average global score was 28.8±8.6 [Figures 3.1, 3.2, 3.3, 3.4, 3.5, 3.6, 3.7, 3.8].

Discussions

During daily life, people living with HIV frequently face up to discrimination and negative public attitudes leading to the disturbance of own perception of illness [11]. Stigma and discrimination against PLWH are variable by geographical region, race, gender, culture and religious believes. The stigmatization of PLWH has consequences on professional employment, education and health care, as well as on the coping ability. Commonly, multiple stigmatizing situations interfere with HIV, including poverty, sexual orientation, drug use, poor education, detention, violence, nutrition, mental health and physical appearance [12].

Romanian young PLWH have done that since early childhood, experiencing premature discrimination and frequent exclusion during basic education. Growing up with HIV is accompanied by emotional immaturity, low self efficacy to the adult age and commonly a special perception of the illness.

Most nosocomially infected patients are aware that they were innocent victims of medical neglect many years ago [Figure 1, Figure 2].

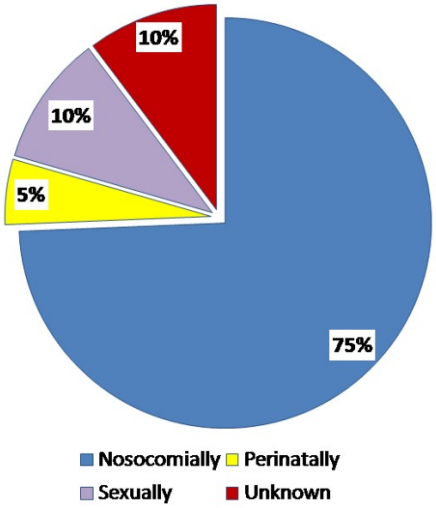

Figure 1: *Distribution by way of HIV transmission*

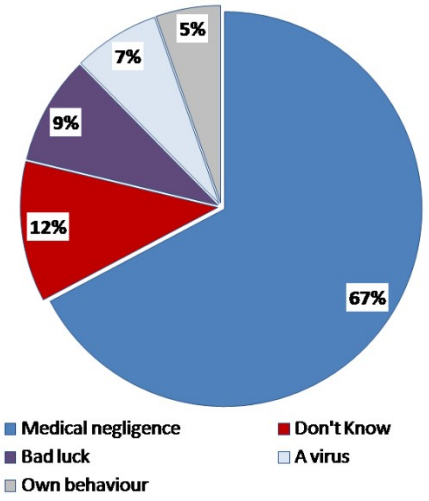

Figure 2: *Distribution by perception of cause of HIV infection*

Regarding the consequences of the disease, we found different perceptions, scaling from extreme low impact (29.5%) to full impact (26%) on daily life [Figure 3.1].

The timeline of HIV was marked by 76.5% patients as incurable infection, according to current science and medical knowledge [Figure 3.2].

Most patients perceived the complete control of the disease, both personal control (63.7%) and treatment induced control (82.3%). The treatment is perceived as more trustworthy than own personal resources for illness control [Figure 3.3, Figure 3.4]. Overall, this perception seems to be realistic and is comparable with the marker of ARVT outcome, evidenced in 70.4% cases by undetectable HIV viral load. Illness identity was not at all perceived by 52.2% of patients and 71.3% cases perceived a score less than 4/10, that could be explained by the efficient ARVT [Figure 3.5].

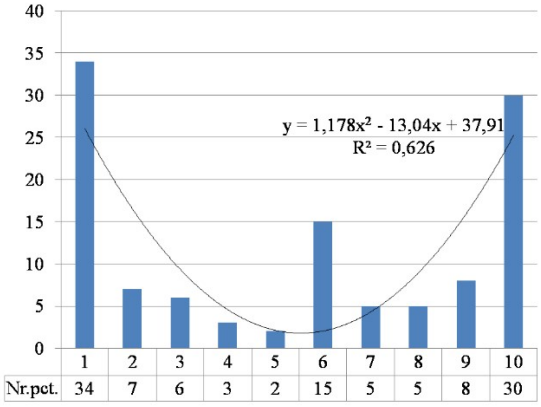

Figure 3.1: Perception of illness consequences

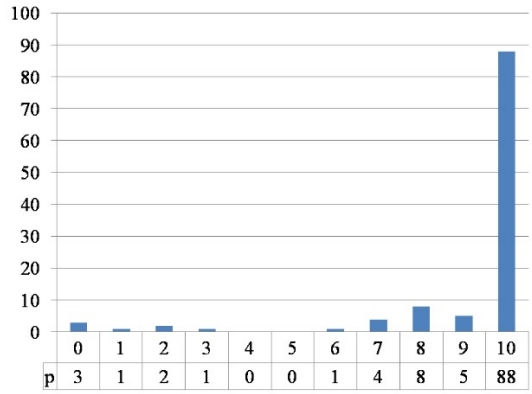

Figure 3.2: Perception of illness timeline

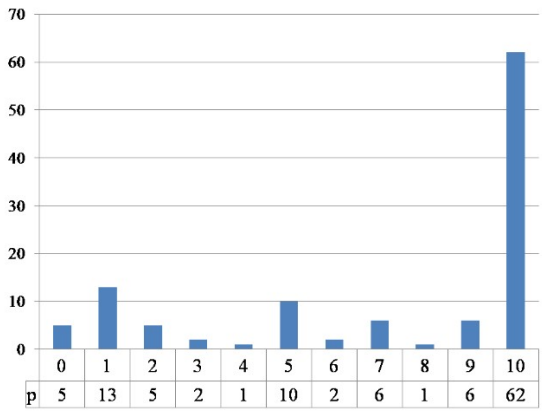

Figure 3.3: Perception of illness personal control

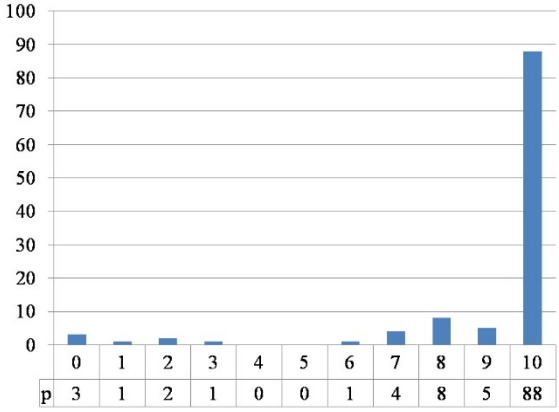

Figure 3.4: Perception of illness treatment control

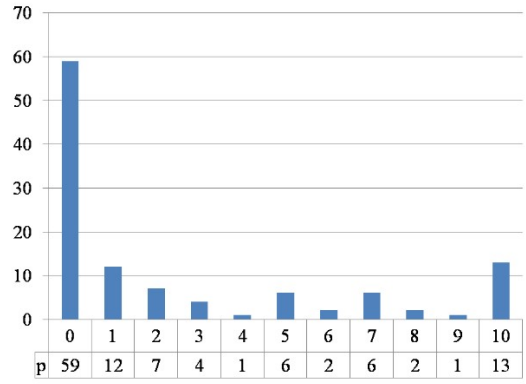

Figure 3.5: Perception of illness identity

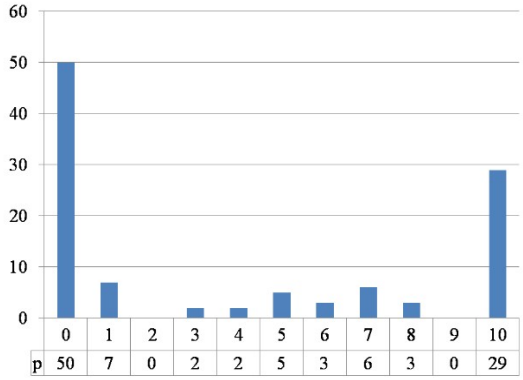

Figure 3.6: Perception of illness concern

Coherence means that patients understand their disease. Over a half of patients consider they fully comprehend the illness [Figure 3.7].

Emotions were perceived by the scale of concern and emotional representation. Most answers expressed no concern (44.25%) and no illness influence for emotional representation (38%) [Figure 3.6, Figure 3.8].

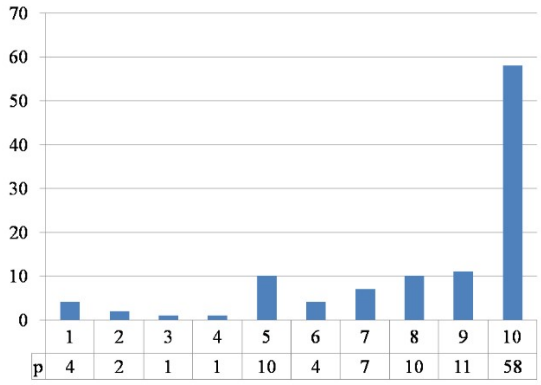

Figure 3.7: Perception of illness coherence

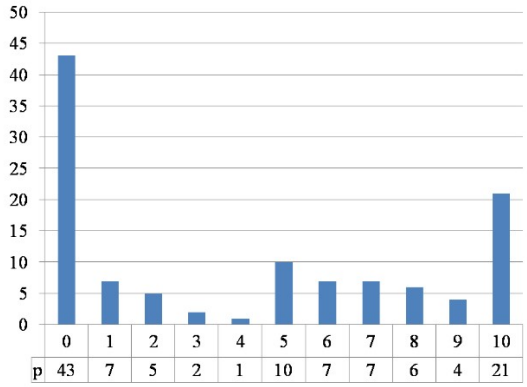

Figure 3.8: Perception of illness emotional representation

Significant corelations of the brief IPQ global score were found with the identy score of symptoms [Figure 4], virologic status (detectable or undetectable) [Figure 5] and female gender [Figure 6]. More intensive perception of infection in HIV infected women was also the result of a previous Brazilian study [13].

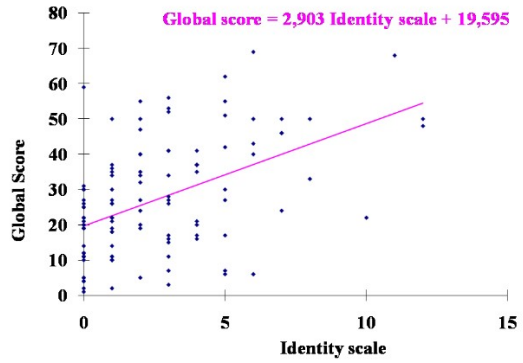

Figure 4: Correlation of global score IPQ and identity symptoms score

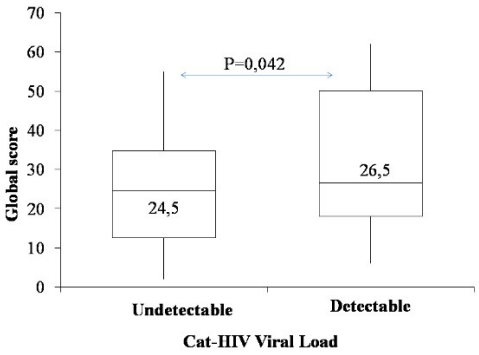

Figure 5: Correlation of global score and category of HV viral load

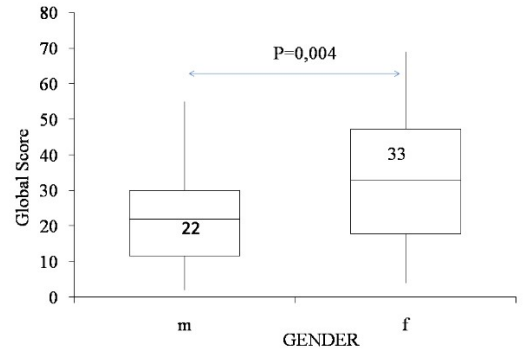

Figure 6: Correlation of global score and gender

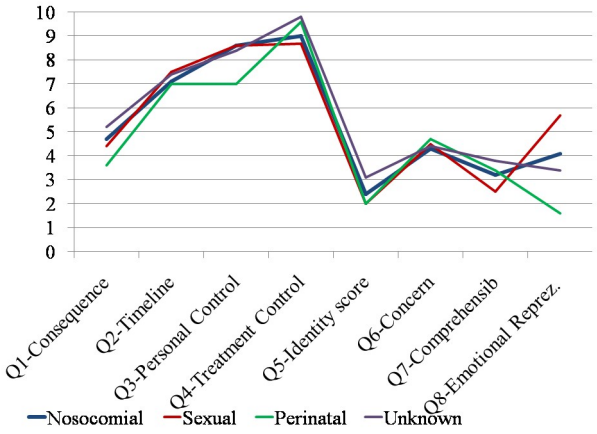

Figure 7: Graphic representation of partial scores of illness perception and HIV transmission ways

The partial scores of the brief IPQ were similar, regardless of the way HIV was transmitted, with the exception of emotional representation, which was more pronounced in sexually infected individuals [Figure 7].

The literature of chronic diseases, including HIV, proved that illness perception influences the experience, management and adherence [10,13]. At a practical level, the evaluation of the IPQ should be used for the management of patient centered care, by focusing on enhancing the

understanding of patient perspective in order to reach the best adherence [14,15,16,17].

Conclusions

Romanian young PLWH have long experienced the disease and are mostly well controlled under the antiretroviral therapy. Women express more negative HIV perception than men.
The perception of the disease correlates with symptom score and virological response to antiretroviral therapy. Exploring the illness perception should be considered good clinical practice for clinician-patient communication, in order to improve the adherence and the quality of life for HIV-infected patients.

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