RESPONSIBILITY AND EXPECTATIONS IN ANTIRETROVIRAL THERAPY – PATIENTS’ VERSUS DOCTORS’ PERSPECTIVE

Maria Alexandra Largu¹, Carmen Dorobăţ², L. Oprea¹, V. Astărăstoae¹, Carmen Manciuc²
University of Medicine and Pharmacy “Grigore T. Popa” - Iasi
Faculty of Medicine
1. Department of Preventive Medicine and Interdisciplinarity
2. Department of Medical Specialties (II)

RESPONSIBILITY AND EXPECTATIONS IN ANTIRETROVIRAL THERAPY – PATIENTS’ VERSUS DOCTORS’ PERSPECTIVE (Abstract). **Aim:** This paper aims to uncover what patients really expect from ART, and also what infectious diseases doctors expect from a patient’s ART regime, thus exploring an important side of adherence to ART. **Material and Methods:** From July to November 2014 we have conducted a qualitative study regarding both patients’ and doctors’ expectations from the ART. We interviewed 30 patients and 4 doctors. We used semi-structured interviews that were conducted in the Psychosocial Compartment of the HIV/AIDS Regional Center in Iasi. **Results:** The patients we interviewed came from all 6 counties in the Moldova area. Age varied from 16 years to 59 years; 55% were female and 45% male. 30% came from a rural area. The most common expectations that patients have regarding ART are: “to help me live”, “not to make me feel sick”, “to be easy to take (not to big, not a lot)”, “not to show on the outside what I have on the inside”. The infectious diseases doctors that we interviewed work in the HIV/AIDS Regional Center in Iasi. Their expectations regarding an ART regimen for patients were: “to reduce HIV viral load”, “to increase CD4 cell count” and “to have minimal impact on the proper functioning of other organs”. Patients consider themselves the only factors responsible for their own ART adherence in 56.6% of cases; 20% consider the doctor to be responsible for their adherence, 16.6% feel that their family, friends, and spouse are responsible, and 6.6% (2 patients) couldn’t answer. Infectious diseases doctors considered that patients are 100% responsible for adhering to antiretroviral therapy. **Conclusions:** In order to assure adherence to the ART it is important to explore both the doctor and the patient’s perspective and to find ways to find a common ground in building a healthy relationship. **Keywords:** HIV/AIDS, ANTIRETROVIRAL THERAPY, ADHERENCE, PATIENTS’ EXPECTATIONS, DOCTORS’ EXPECTATIONS, RESPONSIBILITY.

Antiretroviral therapy (ART) is essential in maintaining a low HIV viral load, which allows the immune system to function properly and assures a qualitative lifestyle for HIV positive patients (1). However, low rates of adherence to ART are still registered, in spite of all efforts.

In Romania, around 90% of all HIV infected individuals are part of the “pediatric cohort” – young people born in 1986-1989 and infected in the hospital. They were diagnosed at the age of 3-5 years and have lived with HIV/AIDS for more than 20 years. They have a history of up to 10 ex-
peripheral drug regimens, having passed from mono – to bi-therapy to HAART (highly active antiretroviral therapy) (2).

The rest of HIV-positive patients are adults infected through unprotected sexual contact or through the use of unsterilized syringes in the case of injecting drug users. They have a shorter history of living with HIV/AIDS and their numbers are continuously increasing.

A highly researched issue regarding people living with HIV/AIDS (PLWHA) is adherence to antiretroviral therapy. Studies identified a number of factors associated with adherence to ART (3,4):

- Medical aspects and characteristics of the therapy - number of pills/day, ART side effects;
- Social aspects – stigma and discrimination, lack of knowledge and understanding of HIV, the doctor-patient relationship, peer support and family support;
- Psychological aspects – treatment fatigue, IQ, psychopathology, treatment fatigue, disclosure of the diagnosis, responsibility, expectations from ART.

This paper aims to uncover what patients really expect form ART, and also what infectious diseases doctors expect from a patient’s ART regime, thus exploring an important side of adherence to ART.

**MATERIAL AND METHODS**

We realized a qualitative study for a period of 5 months, from July to November 2014. We interviewed 30 patients and 4 doctors. The patients came from all 6 counties in the Moldova area – Iasi, Vaslui, Bacau, Botosani, Suceava, Neamt. The infectious diseases doctors that we interviewed work in the HIV/AIDS Regional Center in Iasi.

We used semi-structured interviews as a method of gathering data. The interviews were conducted in the Psychosocial Department of the HIV/AIDS Regional Center in Iasi.

The demographics revealed 55% were female and 45% male (fig. 1); 30% came from a rural area (fig. 2). Age varied from 16 years to 59 years, in concordance with the requirements of qualitative research.

![Fig 1. Gender distribution](image1)

![Fig 2. Environment distribution](image2)

**RESULTS**

Patients’ expectations revolved around general health and a healthy appearance.

The most common expectations that patients have regarding ART were:

- “to help me live” – Patients fear death, especially due to myths about HIV/AIDS. One of the first questions patients ask after diagnosis is how long they have to live;
- “not to make me feel sick” – Patients fear antiretroviral drug side effects, such as nausea, diarrhea, headaches, skin rash, etc. They expect a therapy that makes them feel better instead of worse;
- “to be easy to take (not to big, not a lot)” – Some patients have difficulty swallowing large pills. Having to take too many
pills a day is an often evoked reason for non-adherence;

- “not to show on the outside what I have on the inside” – The stigma associated with the HIV infection is something that patients often fear. They expect that ART would make have minimal impact on their exterior appearance. This offers a sense of security, because society cannot tell they suffer from this disease.

Patients’ expectations from ART show the importance they give to the impact that the therapy has on their overall quality of life, especially on their body’s reaction to medication.

The infectious diseases doctors that we interviewed work in the HIV/AIDS Regional Center in Iasi. Their expectations regarding an ART regimen for patients were: “to reduce HIV viral load”, “to increase CD4 cell count” and “to have minimal impact on the proper functioning of other organs”. Doctors expect pragmatic results from the ART, focusing on the medical aspects.

Patients consider themselves the only factors responsible for their own ART adherence in 56.6% of cases; 20% consider the doctor to be responsible for their adherence, 16.6% feel that their family, friends, and spouse are responsible, and 6.6% (2 patients) couldn’t answer (fig. 3).

![Fig. 3. Patients’ perception of responsibility for adherence to antiretroviral therapy](image-url)

Infectious diseases doctors considered that patients are 100% responsible for adhering to the antiretroviral therapy.

**DISCUSSION**

Exploring patients’ expectations from ART reveals the importance they give to the impact that the therapy has on their overall quality of life, especially on their body’s reaction to medication (5). Multiple side effects, such as nausea, diarrhea, headaches, skin rash, etc or a large number of pills to take are, for patients, signs that the therapy did not meet their expectations and therefore a reason to stop taking it (6). This is an important aspect in working towards adherence to antiretroviral therapy.

Doctors expect pragmatic results from the ART. Their perspective is centered on medical aspects.

Even though both doctor and patient aim for a higher quality of life, the meaning of this concept is often different. This is why often the doctor-patient relationship has to suffer.

Also, doctors consider patients to be fully responsible for their adherence. Patients, however, attribute responsibility to
outside factors in a high percent, considering that adherence is controlled by other people as well as themselves. It is important to understand this aspect that is essential in working towards an optimal adherence (7,8).

The role of a psychologist or counselor is crucial in dealing with this adherence. It is essential that the patient is evaluated from a psychological point of view and that every aspect of his/her expectations about ART is explored.

In order to assure adherence to the ART it is very useful to find common ground between the patient and the doctor. Building a healthy relationship is essential in monitoring the HIV positive patient and in encouraging adherence.

Education is important in every moment of the patient’s life, in order to assure full assumption of responsibility, a key factor in adherence to ART.

CONCLUSIONS

In our research, we realized that, in order to assure adherence to the ART it is important to explore both the doctor and the patient’s perspective and to find a common ground in building a healthy relationship. Both parties have the same main objective — to improve the patient’s health status and quality of life. However, doctors see this objective reflected in the viral and immunological status, where as patients see it in psychological aspects and social integration. It is essential for both to realize the common direction their actions and expectations have, and to work together in achieving goals. The differences in perspective need to be addressed by both parties and it is essential to have support from a psychologist.

ACKNOWLEDGEMENTS

This paper was supported financially by the project: Program de excelenta in cercetare doctorală si postdoctorală multidisciplinara in bolile cronice, contract POSDRU /159/1.5/S/133377, beneficiary U. M. P. "Gr. T. Popa" Iasi, financed from the European Social Fund through Sectoral Operational Programme Human Resources Development 2007-2013.

REFERENCES