



# An Assessment of the Needs of People Living With HIV in Macedonia



**X. E. P. A.**  
ассоциация за хронично вирусно и инфективно

A Member Association of



**IPPF** International  
Planned Parenthood  
Federation  
European Network



**H.E.R.A.**

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# ACRONYMS

**ART** – Antiretroviral therapy

**VCCT** – Voluntary and Confidential Counseling and Testing for HIV

**CA** – Citizens' association

**PLHIV** – People living with HIV

**WHO** – World Health Organization

**AIDS** – Acquired immunodeficiency syndrome

**SRH** – Sexual and reproductive health

**H.E.R.A.** – Health Education and Research Association

**HIV** – Human immunodeficiency virus

## GRATITUDE

We would like to thank all the people living with HIV who took part in the research and openly spoke about the needs and challenges which they face on a daily basis. Their participation may be the first step to including PLHIV, the most concerned, in the processes of improving the HIV/AIDS situation.

The key findings of the research will be shared with all relevant parties in the state in order for them to contribute to the improvement of HIV/AIDS politics and programmes in the state, in particular in the creation of supporting public-health and social atmosphere for the complete realization of the rights of people living with HIV. Hence, the identified challenges will become part of all the implemented HIV/AIDS programmes in Macedonia.

We most sincerely hope to contribute to the creation of a society where PLHIV and their families would practice their freedoms and rights liberated from stigma and discrimination, and where they would have access to high quality care and therapy.

# INTRODUCTION

The Republic of Macedonia is a country with a low rate of HIV/AIDS and with the lowest number of registered HIV-positive people in the south-east European region.

The first case of HIV was registered in 1987, and the first case of AIDS two years later, in 1989. Since the first registered case till now there are in total 118 registered cases of HIV/AIDS in the country. Still, the data on the HIV infection trend in the past 20 years shows continuing increase and around 50% of the HIV-positive cases in the country were registered in the past 5 years.

In 2009 there were 7 new registered cases of HIV/AIDS, one of them with AIDS and 6 people with an HIV-positive status<sup>1</sup>. The official statistics state that heterosexual transmission is dominant for the transmission of the HIV infection.

In 2005 as a result of the cooperation between the Health Education Research Association (H.E.R.A.) and the Clinic for Infectious Diseases the first Centre for Treatment and Psycho-social support of PLHIV and their closest family – “Counseling Centre for HIV/AIDS” (henceforth in the text Counseling Centre) was opened. At the moment the Counseling Centre is the only specialized service in the country of this kind to offer psycho-social and medical services for PLHIV and their families. The Counseling Center's personnel consists of specialists – infectologists, nurses, a social worker and a psychologist, as well as accredited counselors for voluntary and confidential counseling and testing (VCCT). From 2009 the services provided within the framework of the Counseling Centre are covered by the Budget of the Republic of Macedonia and the Preventive Programme for the Protection of the Population from HIV/AIDS.

The death rate in HIV-positive people to date has been quite high, considering the fact that a great number of people were registered in a late stadium of AIDS. The total number of people living with HIV who use the services of the HIV/AIDS Counseling Centre at the Clinic for Infectious Diseases and Febrile Conditions is around 35. The research encompassed 24 people or 68.6 % of the total number of clients.

In accordance with the national protocols on treatment and care ART was introduced for the first time in Macedonia in 2005 with “first-line” drugs according to WHO and extended with new “second-line” drugs in 2006. The cumulative number of people undergoing ART till November 2009 was 23. The therapy for PLHIV in the Republic of Macedonia is offered in centralized manner, within the framework of the Clinic for Infectious Diseases and Febrile Conditions, which currently is the only referent institution for medical care and treatment. The capacity of the Clinic was improved with the opening of the new department for hospitalization of HIV-positive patients, whereas in 2007 a new monitoring equipment for the HIV infection was introduced (CD4 and viral loading).

The treatment with antiretroviral therapy, as well as the treatment for opportunistic infections is covered by the Global Fund and the National Program for Prevention of HIV/AIDS.

The Citizens' Association H.E.R.A. in its practice has registered a number of cases of violation of human rights of PLHIV, related to workplace discrimination and difficult access to health services. Although these people faced stigma and discrimination, they did not use the legal mechanisms because of fear or insufficient motivation in order to deal with the violation of their human rights. Very often, the media itself took part in the violation of the privacy and confidentiality of PLHIV by revealing their identity. Sensational media reporting regarding PLHIV is still present and leads to inducing fear among citizens and deterioration of the prejudices and stereotypes about HIV among the general population.

There are no organized or informal groups of PLHIV that would represent the rights and interests of this community in the Republic of Macedonia. However, in 2009, H.E.R.A. initiated activities for involvement of PLHIV through their active participation in the elaboration of its Policy and Protocol on HIV/AIDS, as well as organizing coordinative meetings and trainings for building capacities. Prior to the moment of publication of this Report, an informal group of PLHIV was formed, consisting of 10 people, which is at the start of its organized activities.

# GOALS OF THE RESEARCH

The goal of the research is to create a preliminary draft of the condition and the necessities of PLHIV regarding different aspects of their physical, psychological and social functioning, with a particular view on the fields of key importance to PLHIV.

## **The more specific goals of the research are the following:**

- To acquire a better insight into the social profile of PLHIV in Macedonia;
- To identify the health and psycho-social needs of PLHIV;
- To determine the level and the forms of stigma and discrimination to which PLHIV are exposed in society, including the issue of self-stigma;
- To identify the level of information on the part of PLHIV regarding their rights, the national and international HIV/AIDS policy and instruments;
- To achieve better understanding of the preparedness and the manners of active involvement of PLHIV in the creation and implementation of HIV/AIDS programs, as well as an active participation in the protection and application of their rights and needs;
- To identify the level of disclosure of the HIV status by PLHIV and the challenges caused by hiding the status;
- To identify the needs and challenges of treatment among PLHIV;
- To identify the level of information on the possibilities of being a parent living with HIV.

# METHODOLOGY

The selection of the respondents was intentional, i.e. the selected are clients/patients that use the services of the HIV/AIDS Counseling Centre. The Counseling Centre functions within a partnership between H.E.R.A. and the Clinic for Infectious Diseases and Febrile Conditions.

The research refers to a population which is quite heterogeneous regarding all of its relevant demographic and social characteristics. In order that the sample is more representative, that is with a view towards a more extensive further use of the findings, 68,6% of the population was included. The respondents were people reflecting all kinds of variations within the population.

## Procedure

**Personnel** – the personnel and team of surveyors were appointed by the organizations in charge of the research. Namely, after the determination of the draft-research a questionnaire for gathering data was created, which was then tested on a focus group of three people living with HIV. They contributed to the modification of the questionnaire and its adjustment to the characteristics of the target group with their comments.

A one day training for the surveyors followed. The surveyors were the personnel of H.E.R.A, i.e. social workers with previous experience in offering direct services to PLHIV and their families in the Counseling Centre of the Clinic for Infectious Diseases and Febrile Conditions.

## Time frame August – September 2009

**Recruiting respondents.** The respondents were recruited by the social worker who has direct contact with PLHIV at the HIV/AIDS Counseling Centre. Due to the distinctive nature of the group and particularly the great demand for anonymity and confidentiality, the respondents were contacted by telephone or in person during their visits to the Counseling Centre at the Clinic.

**Gathering data.** The research data were gathered with the help of a questionnaire for the assessment of the PLHIV needs, which was filled out through interviews with the respondents by the inquirers. The questionnaire was composed of open and closed questions. Because of the massiveness of the questionnaire and its complexity, a need arose for certain clients to be assisted while filling out the questionnaire regarding unknown terms. The interviews were held in the Counseling Centre at the Clinic for Infectious Diseases, the

H.E.R.A. offices, the homes of PLHIV and other places suggested by PLHIV themselves. Each of the respondents had a personal meeting with the surveyors. In average, the interviews lasted for 40 minutes.

**Managing the data.** Once the procedure of gathering data was over, the data were introduced into a data base in an operational system for statistic processing of data<sup>2</sup>. The open questions were processed in a quantitative manner, according to the commonness of the answers. An electronic access to the data base was possible only with the use of a password.

**Analysis of the data.** A descriptive processing of the demographic variables of the respondents was made, as well as of their knowledge, experiences and condition regarding the stigma and discrimination they face, access to work, health and social services, self-stigma, variables in the social and other spheres regarded to be crucial by the respondents for the promotion of their status, treatment and sexual and reproductive health. The analysis covered all the respondents. In addition, a correlative analysis of variables which the surveyors deemed to be co-dependent was made.

Because of the applicative character and the scope of the research, the conclusions of this study shall be used for the creation of further broadened research and analyses.

**Distribution of data.** The findings and conclusions of the research shall be primarily used for organizational improvement of work with PLHIV, as well as enhancement of existing policies on advocacy for PLHIV's rights and for building their capacities for autonomous inclusion in the processes of creating and implementing the policies and programs for HIV/AIDS.

Furthermore, we encourage all the decision makers in the country (government institutions, citizens' organizations, media, informal citizens' groups) to actively participate in the improvement of national HIV/AIDS policies and programs, which are directly related to the PLHIV and in the creation of supportive public-health and social environment for full application of the rights and necessities of PLHIV.

# ETHICS

**Informed consent.** All of the respondents were informed in detail about the goal of the research, the type of necessary data and the manner of further use of the gathered data, before the interview. Also, all the respondents gave an informed consent to confirm the voluntary participation in the research, to confirm that they have been informed on the possibility to refuse to answer a question and to terminate the participation in the research at any time.

**Anonymity.** The respondents were guaranteed anonymity, i.e. they were only asked for general demographic specifics, rather than to reveal segments of their personal identity. The surveyors that performed the research were people who already knew the HIV status of the respondents and were in daily contact with them through their work, hence the anonymity of the respondents while giving the data was not threatened at any time. In other words, they were not placed in a situation to reveal their status in front of new people during their participation in the research.

**Confidentiality.** H.E.R.A. guaranteed the confidential managing of the data during the whole procedure (processing of data and publication of the research). For this purpose the data issued by the respondents, shall be treated in accordance with the policy on dealing with PLHIV and shall be presented in processed form.

## LIMITATION AND POTENTIAL BIASES

**Bias as to whether the sample is representative.** The sample used in the research is not a random sample, hence all the necessary measures to produce higher representative sample and the possibilities for generalization and broader use of the results were undertaken. Namely, the number of the population of PLHIV using the services of the Counseling Centre is 35 people in total. The respondents' sample in the research is 24 people, i.e. 68.6% of the total population. As was already mentioned, this is a heterogeneous population regarding its social and demographic characteristics, which further on reflects in the sample used in the research.

Bias on the basis of dishonesty and/or socially desirable light. Bearing in mind that certain number of the questions were of a sensitive nature related to the respondents' sexual behavior, personal social relations on one hand, and an assessment of the present services offered by the organization conducting the research and the established intimacy between the service providers and the respondents, on the other hand, it can be expected that certain part of the answers were shown in a socially desirable light.

## RESULTS:

# GENERAL INFORMATION

## Demographic characteristics

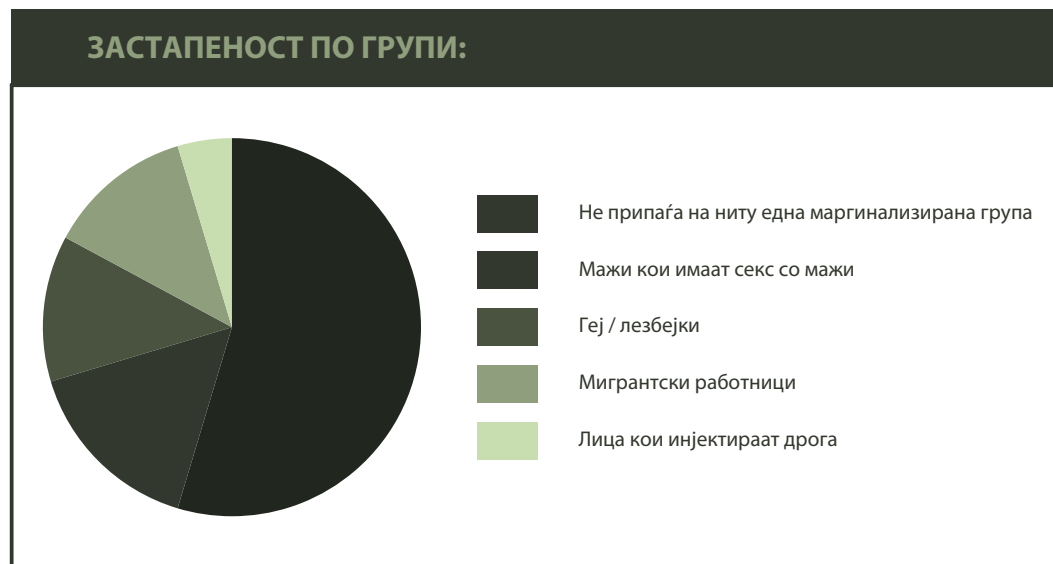
Sex		Age				Monthly income calculated for each member of the family		
Male	Female	25-29	30-39	40-49	50-____	Up to 4000 MKD	4000 - 8000	Over 8000 MKD
75%	25%	16,7%	54,2%	16,7%	12,5%	28,6%	23,8%	47,6%
Level of education					Working status			
Elementary	High School	Masters	Specialists	Doctoral studies	Full time employment	Part time employment	Self-employed	Unemployed
25%	37,5%	16,7%	16,7%	4,2%	29,2%	12,5%	12,5%	33,3%

Regarding the time of their awareness of the HIV-positive status, the greater part of the respondents (45.8%) stated a period of 1-4 year, one quarter (25%) stated a period of 4-9 years, while 20% responded that they discovered their HIV-positive status within the past year. Small number of respondents (8.4%) stated that they had known their HIV status for longer than 10 years.

On the question about their present partner, most of the respondents stated that they are single, 41.7 %, almost a third (33 %) stated that they are married and living with their partner, while 12.5 % of the respondents stated their status to be of a widow/widower. Very small percent – 4.2 are married and not living with their partner, 4.2% are in a relationship and living with their partners, while 4.2% are divorced.

From those who reported to have a spouse/partner, most of them, 70% have been together with their spouse/partner longer than 4 years. (40 % in the time frame of 4-9 years and 30% in the time frame of 10-14 years). Smaller percent of the respondents (20%) stated to be together for more than 15 years, and only 10% to be together with their partner during the past year.

When asked whether they declare themselves to be members of some of the vulnerable groups regarding HIV, respondents were placed in the following categories:.



Regarding the level of education, most of the respondents, 37.5% have a high-school degree, 25% graduated from elementary school, 16.7% have master degrees and the same percentage (16.7%) specialized in a certain field. One person or 4.2% has a degree in doctoral studies.

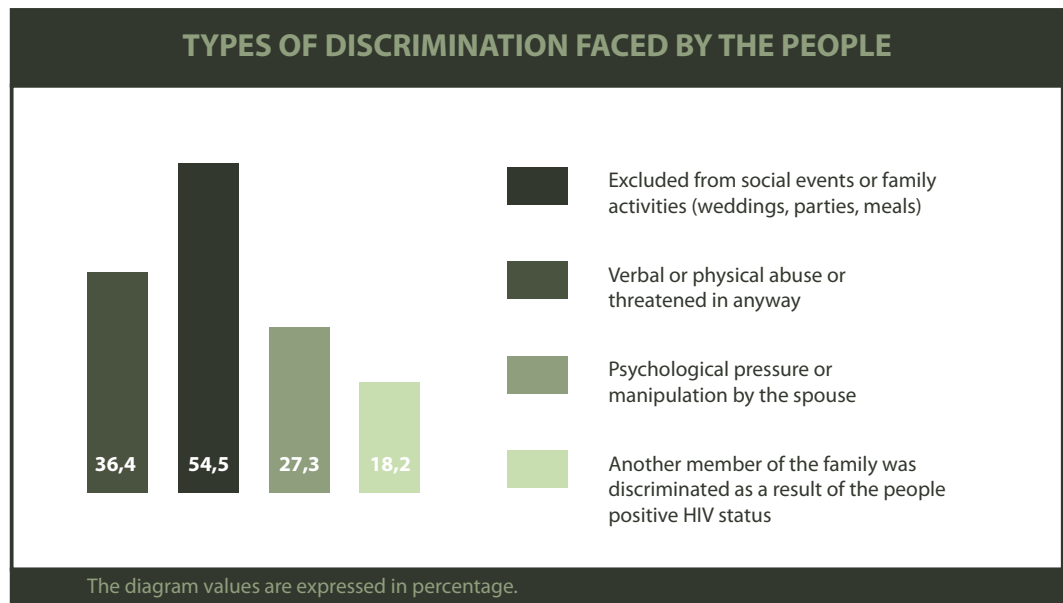
Regarding the employment status, most of the respondents (33.3%) stated that they have no incomes (unemployed/not part-time workers), 29.2% are employed with full time job, smaller percent, 12.5 are self-employed, and the same percent (12.5%) are part-time workers.

# STIGMA AND DISCRIMINATION

Regarding the question who knows the respondents' HIV status, they were grouped into 4 categories:

- people whose status is known only by the immediate family circle and close friends – 29.2;
- people whose status is known by the immediate family, close friends and health workers – 58.3%;
- people whose HIV status is known by the immediate family, close friends, health workers, collaborators and employers – 8.3%
- people who are not hiding and publicly reveal their status – 8.3%

45.8% from the total number of the respondents stated to have faced some kind of discrimination by other people as a result of their HIV status. This percentage, in accordance with the manner of discrimination issued the following answers::



Regarding the question on the reason of discrimination/facing stigma by other people, most of the respondents (66.5%) stated the reason to be lack of knowledge on the transmission of HIV virus, while 30.8% do not know the reasons for the discrimination.

37.5 % of the respondents listed the people/institutions/organizations which discriminated or stigmatized them. Most of them (77.8%) stated to have been stigmatized/discriminated by health workers employed in state health institutions (Microbiology Clinic, Military Hospital, Gynecology Clinic, Clinic of Ophthalmology, Dentistry Clinic, Rentgenology Clinic, Policlinics Bit Pazar, Surgery), 11.1% stated to have been stigmatized/discriminated by health workers employed in a private health institution, while 33.3% stated to have had any experience with stigma and discrimination at their work place (state health institution, educational institution, financial state institution).



## ACCESSTO WORK, HEALTH AND SOCIAL SERVICES

The employers of only 3 people or 12.4% of the total number of the respondents know/knew about their HIV status, where upon in the three cases the employer found out by other people, without the consent of the client. Two of them (66.7%) reported to have been fired on the grounds of their HIV status. One of the people (who worked in a state institution) was forced to resign, while the other person (who also worked in a state institution) was ordered not to come to work, but remained to be employed and continued to receive a regular salary.

One person, although not fired, reported an attempt for transference from the former position on the grounds of the HIV status, but after an intervention from a specialist physician, remained on the current position. Both people (the person who was fired and the person who was supposed to be transferred from his/her position) have not shared their HIV status with the present employer.

Regarding the health services they receive, 70.8% reported that a health worker knows their HIV status (the primary healthcare provider, gynecologist, dentist and other medical profiles). It is interesting to mention that they have disclosed this information to the health worker themselves.

29.1% of the respondents who answered that the health workers were informed on their status, stated that they had never been refused a medical service as a result of their HIV status.

11.8% of these respondents were refused service related to their sexual and reproductive health.

Regarding receiving social services, not one of the people disclosed their HIV status to the social worker, hence discrimination in the area of receiving social services cannot be calculated.

### **70.8% consider that there is a lack of services for PLHIV in Macedonia.**

Regarding the services missing, the respondents gave the following answers:

- 29.4% listed the social benefits on the grounds of a positive HIV status (shorter working hours, transference on another working position, retirement, day care facilities);
- the same percent (29.4%) stated that there is a lack of self-help/lobbying group for their rights as well as for access to ART in Macedonia;
- 17.7% listed the lack of dispersed centers for HIV/AIDS in the country.

50% of the respondents stated that they will reveal their HIV status in order to realize some type of benefit, if it exists (e.g. one-time financial help, free health service).

Less than half of the respondents (45.8%) did not list a need for service to be introduced within the framework of H.E.R.A./Clinic's Counseling Centre. From those who listed the necessity for introducing services in the Counseling Centre, 30.8% are hold the opinion that there is a lack of meetings/groups for self-support for PLHIV. The same percent considers that there is a need for bigger privacy among PLHIV in cases when they don't want to communicate among themselves/meeting with the doctor without the presence of another PLHIV, while 15.4% consider that the patients' medical files should be locked and kept under passwords.

## SELF-STIGMA

Regarding the feelings related to self-stigma, most of the respondents (70.8%) stated that they blame themselves for their HIV status, while 50% that they feel guilty for their HIV status. (33.3%) feel ashamed of their HIV status, and the same percent (33.3%) have/had low self-confidence as a result of the HIV-positive status. 20.8% blame/blamed other people for their HIV status, while 20.8% have/had suicidal ideas as a result of their HIV status and 8.2% have the feeling that they should be punished.

When it comes to specific actions that the respondents have/have not undertaken due to their HIV status most of them (66.6%) stated that they have decided not to have children at all or not to have any more children. Less than half (45.8%) of the respondents stated that as a result of their HIV-positive status they have decided not to get married, while 41.7% of the respondents decided not to have sex any longer. Smaller percent of the respondents (25%) have chosen not to attend social gatherings/meetings as a result of their HIV-positive status, 23% avoid the local health clinic when they have a need for its service, while 20% have stopped with the education/trainings. 16.7% decided not to apply for jobs/promotions and 8.3% decided to stop working.

More than half (54.2%) stated they have surpassed the situation, 29.2% have not tried to change anything, while 12% responded that they are considering/hoping for a change in the future/are in the middle of a change.

## RIGHTS, LAWS AND PUBLIC POLICIES

When questioned on the National HIV/AIDS Strategy of the Republic of Macedonia, half of the respondents (50%) stated that they have read it.

A very high percent of the respondents (75%) responded to be aware of the Law on Protection of Patients' Rights.

Regarding the other national and international documents related to HIV/AIDS and the rights of PLHIV, only 29.2% responded to have heard/read them.

16.7% of the respondents confirmed to have been forced to medical procedure on the ground of their HIV status. Small percentage of the respondents (8.3%) answered that they have been isolated, placed into quarantine or separated as a result of their HIV positive status, while the same percentage answered they had to reveal their HIV status while entering another country.

High percent of the respondents (79.2%) stated that none of the mentioned activities that reflect a relation/policy of discrimination towards HIV status (1. forced to medical procedure; 2. isolated, placed in quarantine, separated; 3. forced to reveal his/her status while entering another country; 4. forced to reveal his/her status while applying for citizenship/dwelling; 5. arrested, taken to court on the grounds of charges related to HIV status) have happened to them due to their HIV status.

Less than half of the respondents (45.8%) regarding the question of whether their rights have been violated answered NO, 25% answered YES while 29.2% answered that they cannot be certain about it. 3 of those who gave a positive answer stated that their right to privacy has been violated during hospitalization, 1 person stated that their right to informed consent for an HIV-test had been violated and 2 people stated that their right to efficient health protection was violated.

None of the people whose rights have been violated have been seeking for legal support. 2 people listed the reason for this to be their fear from disclosure of their HIV status during the procedure, 1 respondent was counseled not to take any action and 1 respondent did not believe that the outcome of the procedure would be successful.

## CHANGES

Most of the respondents (70.8%) answered that they know an institution/organization that can help them should they be discriminated or stigmatized. Very high percent of them (88.5%) revealed that this is a national non-governmental organization, 23.5% gave the name of an international organization, while the same percentage (23.9%) listed the UN. The Public Ombudsman was chosen by 2 people (11.8%).

70.8% of the respondents answered that they know the name of the organization/institution. Most of them (88%) listed the NGO H.E.R.A., while 29.4% referred to the Helsinki Committee.

When asked whether they had tried to solve a problem of stigma or discrimination, 7 respondents or 29.2% gave an affirmative answer.

It should be noted that although these 7 respondents mentioned specific examples of violation of human rights as the reason for stigma or discrimination, only one of them gave an affirmative answer to the question "Have your rights been violated". One respondent gave a negative answer, while 5 stated that they are not certain whether their human rights had been violated or not.

85.8% of the respondents mentioned one person who had helped them in resolving a problem related to stigma and discrimination: an HIV/AIDS specialist from the Clinic for Infectious Diseases and Febrile Conditions, while 1 respondent mentioned the non-governmental organizations.

As one of the most important issues that should be addressed by the NGOs fighting against stigma and discrimination against PLHIV, most of the respondents (45.8%) identified lobbying for the rights of PLHIV, while the same percentage (45.8%) mentioned offering assistance to PLHIV by emotional support. 41.7% stated that raising awareness and informing the wider public about AIDS was the most important issue.

When asked about establishing communication among PLHIV half of the respondents (58.3%) answered affirmative on further communication with other PLHIV (37.5% stated that they already are communicating with some of the PLHIV and have nothing against increasing this number, while 20.8% answered that they didn't communicate with other PLHIV at the moment, but would like to). Smaller percentage (20.8) of the respondents declared that they do not want to communicate with other PLHIV, 16.7% are prepared to communicate with only a small number of people, and 4.2% stated that they communicate only with certain people and do not want this to change.

Regarding the reason for further communication with other PLHIV, most of the respondents (62.5%) pointed to peer support and help among PLHIV, while 41.7% pointed to the exchange of experiences and information among PLHIV as the reason.

More than half (58.3%) stated that they wanted to be a member of a PLHIV group.

Also, most of the people (62.5%) gave an affirmative answer regarding introduction of training of PLHIV.

60% of the respondents who answered that they wanted to participate in a training, were mostly interested about the issue of treatment, 46.7% about HIV/AIDS and prevention, 46.7% on the possible ways of self-organization of PLHIV and the same percentage (46.7%) were interested about healthy lifestyles.

Most of the half (58.3%) answered that they would like to be included in the activities related to HIV/AIDS within the framework of the Citizens' Association H.E.R.A., and the same percent would like to participate in the establishment of a citizens' association of PLHIV.

## TESTING AND DIAGNOSIS

As a reason for doing the HIV test most of the respondents (33.3%) mentioned suspicious symptoms. 16.7% stated that they did the HIV test because their partner was HIV-positive, and the same percentage (16.7%) stated that they just wanted to know their status. A very small percent 4.2% did the test due to illness/death of their partner. Out of those who chose the option 'other' in the answer, 2 people stated that they discovered their HIV status during a procedure of donating blood, 1 person was forced to do the test in a prison, 1 person did the test before leaving to work in another country, 1 person was tested without his/her knowledge and 1 person did the test upon the suggestion of the primary care physician even though he/she did not exhibit any of the symptoms.

Regarding the decision to make the HIV test, most of them (70.8%) stated that it was voluntarily, while the other 29.2% stated that they were tested without their knowledge and found out about their HIV status once the test was made.

Half of the respondents (50%) during the testing received pre and post HIV counseling, less than half (41.7%) received only post HIV counseling, while 8.2% did not receive any form of counseling during the testing for HIV.

When asked the open question about the challenges and problems regarding HIV testing in Macedonia, most of the respondents 66.7% mentioned problem/challenges. 25% listed the emotional aspect while receiving the results as the biggest problem. 16.7% of the respondents identified confidentiality and protection of data of people with a positive HIV result as a problem, while the same percentage (16.7%) hold the opinion that HIV testing according to the VCCT principle is widely present in Macedonia.

## REVEALING THE STATUS

Regarding their HIV status, most of the respondents (41.7%) shared this information with 1-3 people, 20.8% of the respondents shared it with 4-6 people, while 16.7% with 7-15. a small percentage (8.3%) stated that they do not hide their HIV status and more than 15 people know it. 4.3% have not shared their HIV status with anyone.

Regarding the manner of disclosing their HIV status with other people, 66.7% of the respondents' spouses know about their HIV status. Most of them (87.5%) revealed it themselves. The partners/spouses of a small number of them (6.2%) are not aware of the person's HIV status, while the same percentage were told by another person, without the client's consent.

Most of the respondents' parents (61.9%) do not know about their child's HIV positive status, while 33.3% of the respondents told the parents themselves. The rest 4.8% of the respondents' parents were told by another people without the consent of the PLHIV.

Most of the respondents' siblings (47.6%) do not know about their HIV status, 28.6% were told by the respondents themselves. In 14.3% of the respondents another person told their siblings about their HIV positive status without their own consent. 9.5% of them stated that the information was given by another person, but with their consent.

A very high percent from the 50% of the respondents who have children, (91.7%) did not tell their children about their HIV status, while the rest 8.3% told them themselves.

The friends of most of the respondents (45.8%) do not know about the respondents' HIV status, while 41.7% of the respondents revealed their HIV status to the friends themselves. Small percentage (8.2%) were told by another person without the respondent's consent.

High percent (86.4%) of the respondents' neighbors do not know about the HIV status of their neighbors, while 13.6% found out from another people, without the respondent's consent.

In 78.3% the other adult members of the family do not know the HIV status of the respondents, while a very small percentages (4.3%) were told by another person without the PLHIV's consent.

With 58.3% of those who have collaborators, most of the collaborators do not know the respondents' status (78.6%), 14.3% know from the respondents themselves while 7.1% found out from another person without the respondent's consent.

Of the respondents who have employers (45.8%) in most of the cases (81.8%) the employer does not know about the respondent's status, while 18.2% found out from another person without the respondent's consent.

Most of the respondents (45.5%) told their HIV status to the primary care physician themselves, while in 40% their physicians do not know the HIV status of the PLHIV.

From the total number of respondents that used the services of a dentist (75% of the respondents) in most of the cases, 77.8% the dentist did not know their HIV status, 16.7% told the dentist themselves, while in 5.6% of the cases another person told without the respondent's consent.

From the respondents who use the services of a gynecologist (20.8%) in most cases (60%) the gynecologist does not know the HIV status of the patient, 20% were told by the patient, while the same percentage (20%) found out from another person without the respondent's consent.

A high percentage of the respondents (80%) did not reveal their HIV status to the rest of the health workers.

Only 20% of all the respondents contacted a social worker in an institution and not one of them revealed their HIV status to the social worker.

The media found out of a respondent's HIV positive status in only one case, from another person without the respondent's consent.

Concerning the attitude of the closest friends and family who are aware of the HIV status of the respondents, the results are as follows:

Most of the spouses/partners (42.9%) have had very supportive reactions towards the respondents. Most of the parents (75%), as well as a very high percent (72.7%) of the siblings who know of the status are also supportive towards the respondents.

Most of the friends (50%) act in a supportive manner towards the respondents, and in 50% of the cases the primary care physician did not change the attitude upon becoming aware of the status Likewise, 50% of the respondents' dentists who know their patients' HIV status have acted in a supportive manner.

91.7% of the respondents answered the open question on the problems and challenges related to revealing and confidentiality of the status. 95.5% of them pointed fear of stigma and discrimination in society on the grounds of their HIV positive status (isolation, contempt, labeling, prejudice, social exclusion, fear from having an unsafe life, losing the job etc.)

## TREATMENT

Regarding the current health condition of PLHIV 37.8% assessed it as excellent, with the same percentage 37.8% stating that their health condition is good. Smaller percentage, 20.8% consider that their condition is very good while a very small percent (4.2%) stated that their current health condition is bad.

At the moment of conducting the research most of the respondents (70.8%) are taking ART.

95.8% of the respondents consider that ART is available at the moment in Macedonia, regardless of the fact whether they are taking it or not.

The open question on the challenges and problems of ART in the Republic of Macedonia was answered by 70.8%. Most of them (70.6%) identified the maintenance of ART (providing ART by the state) as one of the main problems. 23.5% stated that apart from ART they have a need for free/reduced price complementary and other type of therapy related to the HIV status, while 17.6% consider that there is a shortage of a broad specter of ART combinations.

## REPRODUCTIVE HEALTH

Less than half of the respondents (45.8%) have children and out of this percent only 1 person has a child with a positive HIV status.

More than half of the respondents (54.2%) stated that once they have been diagnosed they have not received counseling from a health worker regarding their options on reproduction.

Small percent of them (8.3%) were counseled by a health worker not to have children since they are HIV-positive.

When asked what the main problems and challenges for having children were, 87% of the respondents answered the question. Most of them (57%) identified the fear of transmitting HIV to the child as the main problem. Likewise, 33.3% of the people pointed as a problem the lack of laboratory equipment for a procedure of clearing from the semen in the country (so-called sperm-washing), while 14% pointed as a challenge the "in-vitro fertilization" procedure in HIV-positive persons. 19% mentioned the potential stigma and discrimination towards a child infected with HIV.

## DISCUSSION

The description of the social condition of PLHIV has shown that 1/3 of the evaluated do not receive income on any basis and have an average monthly income per member of the that amounts to less than 4,000 MKD (65 Euro).

Almost half of the respondents who revealed their HIV status, felt some form of stigma and discrimination. In most of the cases it appeared as verbal and physical abuse and threatening. In 37% the pressure was made by their spouse.

Furthermore, 37% of the respondents in this group pointed to institutions in which they felt discriminated on the basis of their HIV status. Almost 80% of these PLHIV were discriminated against by health workers employed in state institutions and 11% in private health institutions.

Although the number of cases to have suffered discrimination on the workplace is very small (only 3 respondents) it has to be considered that this is the total number of people whose employers knew about their HIV status. What terrifies is the fact that they did not share this information voluntarily and themselves, due to which they suffered the consequences (two of them were lost their job – one of them was fired, while the other person was asked not to come to job, but continued to receive salary; the third person reported an attempt for dislocation to another position).

Almost 1/3 of the PLHIV point to the lack of special services for HIV/AIDS. More precisely, they ask for social benefits on the grounds of their HIV-positive status, including shorter working hours, reassignment to a more adequate position, retirement, home. The fact that 50% of the PLHIV stated they were prepared to disclose their HIV status in order to receive a certain benefit (social or health) on the grounds of their HIV-positive status, should it be available in the country, is very important.

Around 18% think that there is a lack of dispersed HIV/AIDS services in the country.

30.8% of the respondents suggested the type of services to be introduced in the Counseling Centre: organizing meetings, appointments/groups for PLHIV. In addition, 30.8% think that increasing the privacy in the Counseling Centre in case of meetings with other PLHIV when receiving a health service is crucial.

The level of being self-judgmental, i.e. the self-stigma present in PLHIV is particularly high regarding their sexuality and plans of parenting, with 2/3 of the respondents stating that they have decided not to have children or not to have

any more children as a result of their positive status. Furthermore, almost 50% of the respondents stated that their HIV-positive status made them decide not to get married. In addition, 40% of the respondents decided not to have sexual intercourse any longer, and 1/3 of the PLHIV stated that they haven't tried to change anything in their life and habits in order to continue their daily social functioning.

Although 1/4 of the respondents stated that their human rights were violated, in many cases legal procedure was not undertaken by PLHIV against people and/or institutions that violated their human rights and freedoms.

3/4 declared to have been informed of the Law on Protection of Patients' Rights, yet the results from the assessment show that part of the PLHIV are insufficiently informed or do not recognize when their human rights and freedoms are being violated.

The small number of the respondents who tried to resolve the problems of stigma and discrimination used an informal negotiation of an HIV/AIDS specialist. PLHIV in the Republic of Macedonia do not recognize a state institution which can assist them in reporting the problem of stigma and discrimination, while only 11.8% mentioned the Ombudsman. Most of them mentioned the citizens' associations.

Most of the respondents gave an affirmative answer regarding further communication with the rest of the PLHIV as well as regarding their active participation in different forms of activism. 62.5% would participate in trainings, 58.3% in informal PLHIV groups, 58.3% as members of citizens' associations of PLHIV and 58.3% would be active within the framework of the existing HIV/AIDS programs in H.E.R.A.

50% of the people were tested for HIV without prior counseling and information on the meaning of the HIV test. Also a big part of them (29.2%) were tested for HIV without their knowledge and consent.

Very high percent (92.7%) of the PLHIV in Macedonia have not revealed their HIV-positive status and they have shared it with only a limited number of people in their surroundings. As one of the main problem/challenge related to the disclosure of the HIV status a high percentage 95.5% identified the potential stigma and discrimination in the society on the grounds of their HIV-positive status and its consequences.

It is important to point out that in most of the cases where the status was revealed most of the friends (50%) who knew about the respondents' positive status were supportive, in 50% of the cases, the primary health physicians did not change

their attitude towards the patient after the knowledge about the HIV status, and in also 50% of the cases, the respondents' dentists who knew the status were supportive.

Most of the PLHIV identified providing continuous ART by the state as one of the key problems/challenges regarding treatment in the Republic of Macedonia.

More than half of the PLHIV 54.2% stated that they have not received information/counseling on their options about reproduction.

A high percent (57%) numbered fear of transmitting the virus to the child as one of the main problems/challenges.

Most of the PLHIV (33%) regarding planning of family think that there is an absence of important technological interventions (e.g. sperm washing) that would lower the risk of/avoid the transmission of HIV to the child, while 14.3% hold the opinion that a major challenge is the "in-vitro fertilization" for HIV-positive women.

## CONCLUSIONS

PLHIV do not disclose their HIV status outside the family circle because of the fear that they would be judged and rejected by the surroundings and society, which according to them is not informed about the ways of transmission of HIV. Yet, there are certain cases where PLHIV have disclosed their status to friends and health workers who have given them their support.

Stigma and discrimination appears whenever the HIV-positive status is disclosed, in the health institutions, as well as at the workplace. Most of the violations of the rights of PLHIV, in particular the right to access to health services, the right to privacy and confidentiality of information are identified within the framework of the health institutions. Partially, this can be attributed to the fact that most of the PLHIV have disclosed their status solely to health workers.

Self-stigma and the feeling of isolation and rejection is in most part expressed by people living with HIV/AIDS and is manifested by losing a will to live a normal life, avoiding the everyday social activities and refusing to have sexual life and plans for parenting.

PLHIV need further information regarding leading a safer and healthy sexual and reproductive life.

PLHIV have the need for knowledge and skills in order to recognize when their rights are violated. There is also lack of additional motivation on taking specific legal actions in order to protect their rights due to fear from further stigmatizing and discrimination.

A great part of the PLHIV community lives in worse than average social conditions. There are no dispersed services for HIV/AIDS around the country. This is a problem for those who don't live in the capital and have additional costs when accessing ART.

The PLHIV community has a need to organize itself, build its own capacities and start with actions in the field of planning and implementing the HIV/AIDS programs in Macedonia.

The main priority in the PLHIV community is a continuous access to ART.



# An Assessment of the Needs of People Living With HIV in Macedonia