



# **Mental Health and HIV/AIDS in Serbia**

*Rapid qualitative study on Mental Health problems  
Of People living with HIV*

**GIP Expert Centre for Mental Health and HIV/AIDS in Serbia**

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## **Mission statement on Mental Health and HIV/AIDS**

### **Mental health and HIV/AIDS**

Mental illness is inextricably linked to HIV/AIDS, as a casual factor and as a consequence, while mental health treatment and support for people living with HIV/AIDS is key to both improving their quality of life and preventing the further spread of the infection. The issue is of particular concern to central and Eastern Europe and the Newly Independent States, where the AIDS epidemic is growing fast while rates of mental illness are also rising, and the limited resources and facilities available to treat both conditions pose major challenges.

### **Addressing the needs**

The GIP Mental Health & HIV/AIDS project is a project of the Global Initiative on Psychiatry that addresses the often-overlooked connection between mental health and HIV/AIDS. The Network supports efforts to improve the quality of life and to diminish the suffering of people with HIV/AIDS. The Network strives for increased knowledge regarding the overlap between mental health and HIV/AIDS, and promotes the development of a comprehensive system of mental health assistance to people affected by HIV/AIDS. Furthermore, it supports efforts to increase the understanding of the general public and health professionals and to decrease the stigma associated with mental illness and HIV/AIDS. The Network works through local expert centres that focus their work on research and training, advocacy and awareness building, networking and a wide variety of other interventions.

### **Global Initiative on Psychiatry**

Global Initiative on Psychiatry aims to promote humane, ethical, and effective mental health care through the world, and is particularly active in countries where mental health care is still usually substandard and where patients' human rights are frequently violated. Their work is based upon the underlying principle that every person in the world should have the opportunity to realize his or her full potential as a human being, notwithstanding personal vulnerabilities or life circumstances. Every society, accordingly, has a special obligation to establish a comprehensive system for providing ethical, humane and individualized treatment, care, and rehabilitation, and to counteract the stigmatisation of, and discrimination against, people with mental disorders or histories of mental health treatment.

## **Abbreviations**

AIDS- Acquired Immunodeficiency Syndrome

ART- Antiretroviral therapy

CD4- T helper cell lymphocyte

COR- Sustainable Development Centre

GO- Governmental Organization

HAART- Highly Active Antiretroviral Therapy

HIV- Human Immunodeficiency Virus

IDU- Intravenous drug users

CCS- Clinical Centre of Serbia

NGO- Non-Governmental Organization

PCR- Polymerase chain reaction

PLHIV- Person living with HIV

RAR- Rapid assessment and response

## **Acknowledgments**

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We hereby thank all those who contributed to this study: experts in the fields of mental health and HIV, who shared with us unselfishly their knowledge and experience, colleagues who helped us in this Report writing, and all those who supported us in our work.

We are especially thankful to PLHIV and who, having taken part in focus groups and talking about their psychological problems, contributed to understanding of this problem. We express our outstanding gratitude for their courage!

In research activities we have received much assistance from our colleagues from the Serbian Expert Centre’s parent organization, International Aid Network (IAN), as well as associations of PLHIV, including: AID Plus, Q Club and UPSZ. In particular, we thank the Ministry of Justice for granting us access to Special Prison Hospital and the staff of this institution for willingness to share their rich experience on this topic. We owe our gratitude to the professionals in the area of mental health and HIV who also gave their contribution and took active part in this assessment.

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We hope that this Report will help the decision makers in making their efforts more efficient and effective – in terms of improving the quality of living of PLHIV.

# 1. Introduction

## 1.1 Problem Description

The importance of mental health for quality of life is not adequately recognized in the world; this problem being particularly evident in societies faced with poverty and unfavourable economic and social conditions. The worsening of living conditions in Serbia in the early '90s of the last century, experience of war conflicts in neighbouring countries, disintegration of the ex-country, economic sanctions, bombardment of the country, and a number of additional factors resulted in the worsening of mental health in the general population.<sup>1</sup> At the same time, these factors caused increased impoverishment and weakening of public health infrastructure. The mental health system was particularly affected – the entire quality of services was decreased as the consequence of non-adequate material income.

The importance of mental health, however, was recognized by the World Health Organization (WHO) from the very beginning, as is seen in a definition of health which does not specify just the «absence of disease», but a condition of «full physical, mental and social wellbeing».<sup>2</sup> According to WHO, there is no «official» definition of mental health. Because mental health is defined in different ways depending on culture, subjective assessment, and scientific approach, it is almost impossible to provide a comprehensive definition. The notion of mental health includes a subjective feeling of wellbeing, perceived self-efficiency, autonomy, competence, inter-generation dependence and self-actualization of someone's intellectual and emotional potentials. Professionals generally agree that mental health is something more than a lack of mental disturbances<sup>3</sup>, i.e., the absence of a recognized mental disturbance is not necessarily an indicator of mental health.

People living with HIV (PLHIV) represent a vulnerable group with specific mental health needs. However, these needs are often neglected in HIV Prevention and Treatment Programmes, as professionals and decision makers rarely see a connection between the two problems. On the other hand, mental health problems related to HIV are well documented. Mental illnesses and addiction disorders increase vulnerability for HIV infection and can also be the consequence of HIV diagnosis, due to stigma and discrimination as well as disease progression.

Experience shows that Serbian society has not provided an adequate response in view of the needs of PLHIV, nor has the health system been able to respond to their needs efficiently. This is, in part, because these needs were not viewed as a priority, and also due to the lack of a holistic response to the HIV epidemic on the national level. Such a response would include simultaneous efforts in both treatment and support to PLHIV, as well as prevention and destigmatization programs.

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<sup>1</sup> Mental Health National Commission, Republic of Serbia Ministry of Health (2007): National Strategy in the Field of Mental Health and Action Plan, Belgrade

<sup>2</sup> World Health Organization (2001): The World Health Report-Mental Health: New Understanding, New Hope, World Health Organization, 2001.

<sup>3</sup> The World Health Report-Mental Health (2001): New Understanding, New Hope, World Health Organization: *ibid.*

The only service in Serbia specialized for mental health problems of PLHIV is located in the Belgrade Clinic for Infective and Tropical Diseases – HIV Clinic, where only one psychologist is treating the mental health problems of PLHIV, with long-term experience but no specialized training. Although PLHIV are generally satisfied with service quality at the Clinic, it is perceived that the one psychologist who works there is overexerted due to the limited working time in comparison with the varied needs of patients.<sup>4</sup>

Besides the HIV Clinic, PLHIV may use the services of voluntary counselling and testing (VCT) centres which, due to increased accessibility of centres and promotion of VCT practices, more frequently represent for PLHIV an access point to the Health Protection System. However, these centres exist primarily to provide information and support to clients during the testing process and immediately after learning of their diagnosis. The VCT counsellors are not in the position to provide continuous and adequate psycho-social support, as they are not educated in the treatment of mental health problems related to HIV infection.

Regarding the mental health Service System, PLHIV have access to the primary health protection centres, as well as to specialized hospitals, clinics, and mental health institutes. Although available to all citizens, however, PLHIV rarely utilize these services. One reason for this is that professionals working in such institutions are not educated about treatment issues concerning PLHIV who have mental health problems (i.e. prevalence of mental health issues, extent and relation to disease, HAART, social pressure and discrimination, potential interactions between psychiatric medications and HAART, etc.)

Based on these facts, it is evident that reasons exist for more attention to be paid to the mental health needs of PLHIV. Furthermore, other studies also highlighted the need to explore the potential for a systematic approach in resolving these problems. It is necessary that professionals and the wider public within Serbia learn about the relationship between mental health and HIV infection. Knowledge of the issue may be very helpful to all those working in the field of HIV response, and particularly to professionals interacting directly with PLHIV. Increased awareness among decision makers and those who have the power to influence public opinion may promote recognition of the need to address double stigma (stigma directed toward both PLHIV as well as persons having mental health problems). Mental health specialists may also benefit from increased professional knowledge about PLHIV, in gaining the capacity to provide a higher quality of service. And perhaps the most significant issue is the importance of including PLHIV throughout this promotion, with the aim of establishing a foundation for future interventions based on their experience, interpretation and suggestions.

## **1.2 Related Researches in Serbia and Montenegro**

In Serbia, there are few studies about the quality of life and the needs of PLHIV. Although not a single study has directly addressed the relatedness of mental health and HIV, all of them to a certain extent deal with mental health problems, giving us important insight into their social environment and quality of life.

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<sup>4</sup> Expert Center for Mental Health and HIV, (2007): Mental Health and HIV/AIDS Structure in Serbia

During 2005 and 2006, researchers of Imperial College of London, within the HIV Prevention among Vulnerable Populations Initiative (HPVPI), carried out a qualitative study regarding accessibility, service providing and uncertainty in HIV treatment in Serbia and Montenegro<sup>5</sup>. The research was aimed at understanding the experience of PLHIV in treatment and the impact of such experience on their quality of life. The study was also aimed at studying possibilities and contributing to improvement of the HIV treatment system in Serbia. Data included comprehensive interviews with 42 PLHIV or AIDS and 18 HIV service providers.

The study identified the following basic problems for PLHIV:

- Anxiety due to a shortage of therapy and monitoring tests (measuring CD4 cell count and PCR)-the main reasons for deficit incurring in the therapy delivery were: lack of finance, ineffective management and unclear responsibility lines, bad information exchange, bad communication, HIV not recognized as a priority problem in the health system, and lack of alternative ways of therapy supply<sup>6</sup>.

- Lack of therapy information-anxiety caused by such a treatment context is additionally intensified by the lack of information about therapy within the system (i.e. effects, course and availability of therapy). This leaves PLHIV misinformed, as rumour becomes a fundamental source of information, and increases their anxiety and uncertainty. Also, misinformation detracts from the confidence PLHIV have in their health (medical) system, and alters their perception of their own social position.

- Fear from discrimination -fear from discrimination is seen as the basic factor which makes the access to medical care more difficult. PLHIV estimate that discrimination is most frequently expressed among medical workers. Many PLHIV spoke about how doctors refused to treat them, in direct or indirect way, because of their HIV positive status. Access to treatment is often described as humiliating, exhausting and extremely stressful, particularly in specialized fields like dentistry, gynaecology and surgery, as well as in the primary health protection centres. Personal support at the HIV Clinic is very important for PLHIV and plays a key role in maintaining their physical and mental health.

- Discrimination toward PLHIV exists within the family-support of family members is often limited due to HIV and AIDS social structure as well as a lack of basic understanding about modes of HIV transmission. Insufficient knowledge about viral transmission causes fear within a family and affects the behaviour and attitude of family members towards the HIV positive member, which may result in different levels of physical isolation of the HIV positive member. Sometimes, family members blame the HIV positive member for the social consequences of infection. Such

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<sup>5</sup> Bernejs, S. , Rouds T., Prodanovic, A.; Accessibility, services rendering & uncertainty in HIV treatment, Faculty of Hygiene & Tropical Medicine of London University, UK, DFID, HIV Prevention among Vulnerable Groups Initiative, United Nations Development Program, Belgrade/Podgorica 2006

<sup>6</sup> The Study found that among service providers there is a disagreement in view of the range and seriousness of the therapy delivery problem. While some people consider the situation unacceptable and alarming, the other feel that it is an avoidable effect of HIV treatment within a health system of limited resources, in that, the effects being negligible and manageable.

discrimination and lack of social support negatively impact the ability of PLHIV to cope with the infection.

- Employment difficulties-results of the Imperial College study indicate that the position of PLHIV is more difficult at the labour market after disclosure of their HIV status. Employment difficulties due to positive HIV status directly endanger economic independence of PLHIV and their ability to cope with other HIV related problems, particularly treatment.

To summarize, the Imperial College study offered valuable insights into circumstances having significant impact on PLHIV's living quality. These circumstances include the existence of stigma and discrimination on various levels, and concern because of the inconsistent availability of ART therapies. In terms of PLHIV associating with one another, the study concludes that their capacities in activism and advocacy are very much weakened. The reason for that lies in the stress that PLHIV are facing because of the unpredictable supply of therapy and monitoring tests, as well as a lack of referrals and the general stress of the health system. Altogether, it takes away their energy and ruins their self-confidence to the point that they do not feel capable of actively participating in advocating for their own needs

Findings of Imperial College are also partly confirmed by the study of needs of PLHIV carried out during 2004 and 2005 by NGO - Sustainable Development Centre<sup>7</sup>. This research, based on the active participation of a community of PLHIV in all its phases (designing, development of instruments and data gathering), was the first such research conducted in Serbia and Montenegro. Research instruments were: a questionnaire with open and closed-ended questions, and three focus groups with PLHIV. Within the research, twelve fields of knowledge, attitudes, behaviour and needs of PLHIV were observed. The research included 138 PLHIV.

Some of the most important findings of this study are as follows:

- Research results show that more than one third (36.2%) of the subjects are unemployed. Only one third of the participants have a monthly income exceeding RSD 10.000 (around EUR 130), while one fourth (27.5%) receive a monthly amount ranging from RSD 5.000 to 10.000 (between EUR 65-130)<sup>8</sup>. Regarding disclosure to sexual partners, 84% of participants reported telling their permanent partner about their HIV status. The prevalence of disclosure to "occasional" partners is as follows: 55% answered "always," while 39% stated "never" and 6% reported "sometimes."

- About 85% of the subjects reported being insufficiently included in decision making related to issues of their interest, inadequately represented in the structure and work of the Republican AIDS Commission, and feeling that the Republic of Serbia does not care enough about PLHIV.

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<sup>7</sup> Sustainable Development Centre (2005): Assessment of basic needs of PLHIV, Belgrade

<sup>8</sup> According to the Course, as of October 2004

- Cases of discrimination mostly occur in medical institutions with medical workers (other than in the HIV Clinic of the Clinic for Infective and Tropical Diseases, KCS in Belgrade where they go for treatment).
- 75% subjects state that their colleagues at work do not know of their HIV status, which the authors explain as being due to widespread prejudice toward PLHIV. In cases of human rights violations, almost 85% of the participants did not know who to address to protect their human rights.

Based on this research, the COR Research Team considers that it is necessary to strengthen capacities of PLHIV, with the aim that they self-organize so they may participate in resolving their own problems.

In 2004, in Serbia, a study was carried out about self-concept of PLHIV<sup>9</sup>, with a presumption that a person's awareness of his/her carrying the virus unavoidably induces changes in his/her self-valuation. The study was carried out on a sample of 57 PLHIV, with the use of the self-concept scale, developed by Ph.D. Goran Opačić from the Belgrade Faculty of Philosophy. The scale is comprised of ten subscales which measure self-assessment of different self-concept aspects. Besides the self-concept scale, Spillberg's Anxiety Measuring Scale (STAI1 measures situational anxiety and STAI2 measures anxiety as a character feature) and Beck's Depression Inventory were used in the study.

The obtained results indicate that PLHIV are more depressive, have more expressed external locus control and more expressed emotionality compared to persons with HIV negative status<sup>10</sup>. Such relation to others functions as a defence mechanism aimed at preserving the positive valuation of self. Results also demonstrated that self-perception PLHIV have of social competence and acceptance by the social environment (social-self) is more positive compared to persons with HIV negative status. Feeling that they are fully accepted and recognized by the social environment, however, is, in the current authors' opinion not based on realistic ground, having in mind the fact that in most cases of HIV positive persons (80.7%), the social environment does not know about their disease.

The significance of social acceptance as an aspect of self-concept for PLHIV only points out to their strong defences, caused by fear of social isolation if the social environment learnt about their disease. Therefore, relation with other persons and the need to be accepted in their social environment are specially expressed in PLHIV and, perhaps, it is most important in preserving their general self-respect

The above studies are a witness of expressed stigma and discrimination towards PLHIV in Serbia, which are intensified by insufficient systematic solutions within PLHIV treatment and care, including poorly organized professional assistance system

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<sup>9</sup> Stamenković T: Self-concept of HIV positive persons, Graduation thesis, Belgrade, 2004

<sup>10</sup> PLHIV have significantly higher scores on externality and sensibility scales. Sensibility here is related to finding out if there exists the inclination to more sensible (emotional), that is, more rational reaction in different living situations. Externality is related to finding out if there is external, i.e., internal locus control – locating responsibility for own life beyond or within self, conviction that causes of living events are external, belief in destiny, bad luck, chances). These scales, as understood by their author, have the function of defence mechanisms.

for those PLHIV having mental health problems<sup>11</sup>. The findings also demonstrate feelings of isolation and fear of being rejected by the social environment. As such, acceptance by the social environment and their support may have positive effects on PLHIV mental health.

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<sup>11</sup> Expert Center for Mental Health, HIV & AIDS: Mental Health Structure, HIV & AIDS in Serbia, 2007

## **2. Research Goals and Methodology**

### **2.1. Research Goals**

This research was aimed at studying the quality of life and mental health problems of PLHIV, the sources and context within which such problems occur, as well as the importance of designing responsive, need-based services.

One of the ways to achieve these goals is by utilizing methodology which outlines process and meanings, interpretations and behaviour of people, intending to reach a deeper understanding of mental health problem experienced by PLHIV. Qualitative method RAR (Rapid Assessment and Response), as a means of data gathering was our selected method, having in mind that RAR is considered irreplaceable in studying the phenomena related to complex human behaviour.

By using qualitative methodology, we tried to contribute to understanding the needs of PLHIV, in that we relied on data given to us by the very participants in the research. Findings of this research, together with other findings of studies addressing the quality of life of PLHIV, may be significant in the designing of constructive proposals to alleviate problems faced by most PLHIV.

The primary goal of this research was to assess the span, form, consequences and context of mental health problems experienced by PLHIV. We tried to provide a broader understanding for:

- **What mental health and psychosocial adaptation is like for people with PLHIV**

*What are the mental health problems most frequently faced by PLHIV? Is the relation to others changed after their learning of the positive status and in what way? Which kinds of feelings and moods are dominant and how do they impact performance of everyday obligations, relation to others, sexual behaviour, body manifestations, and risky behaviour?*

- **Which factors related to HIV and HIV treatment impact mental health**

*Which factors have impact on mental health of PLHIV? Do mental health problems have impact on ART taking? Does ART have effects on mental health and what are these like?*

- **How PLHIV manage difficulties, and what strategies they use for problem management.**

*What helps them to feel better? Do they address somebody? If so, who do they address? What would be helpful in the future?*

- **Use of available mental health services**

*Who do they address for help? Do they use any mental health services? If so, what was their experience, and what is their opinion about what should be changed in the response system to mental health problems experienced by PLHIV?*

## 2.2 Research methodology

The research is based on the data obtained through:

- Four focus groups and four in-dept interviews with PLHIV (including IDUs and prisoners) (*See Annex 1*).
- Three interviews with mental health professionals working with PLHIV (including the psychologist at the Centre for HIV/AIDS at the Clinic for Infectious Diseases in Belgrade, as well as a psychologist and a psychiatrist at the Special Prison Hospital).
- A focus group with professionals providing services to PLHIV (*See Annex 2*).
- An interview with Sara Bernays, who has conducted research on HIV treatment access and was able to provide information about the mental health of PLHIV, and especially about PLHIV in prisons.
- A review of available researches, relevant documents and literature, information reviews, and newsletters.

### 2.2.1 Focus groups and interviews

The majority of the data acquired was obtained through the four focus group discussions with PLHIV, providing most of the material which was further analysed. All focus groups were held in Belgrade between December 2006 and March 2007. The first focus group was held in the framework of research on HIV/AIDS service structure and mental health in Serbia, with the aim to assess the need PLHIV have for mental health related services. The contents of this focus group were included in the current study because during the discussion group members began to address the topic of mental health problems within the HIV infection context. Furthermore, one of the groups was held with PLHIV who are also intravenous drug users (IDU).

With the exception of the IDU focus group, all meetings were held at the Expert Centre for HIV, AIDS and Mental Health. The IDU discussion was held at NGO «Veza». Veza implements an IDU Harm Reduction Programme (syringes and needles exchange), and is a familiar and safe place for the users.

Of the four in-dept interviews with PLHIV, two persons were interviewed in prison. The two other interviews took place at the HIV Clinic at the Institute for Infectious and Tropical Diseases in Belgrade.

### Focus group participant recruitment

A total of 19 PLHIV participated in the focus groups. The relatively small number of PLHIV who participated in this research may be related to the recruitment problems recorded in previous studies.<sup>12</sup> In this research, as well, it was difficult to recruit participants who were not associated with each other, as well as younger age

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<sup>12</sup> Study of the Imperiall Coledge faced difficulties in including younger age PLHIV, which, in part, may be explained by their lack of readiness: due to relatively recent learning about the diagnosis and chaotic feelings accompanying it, concern about the staus discovering risks, and rare inclusion into NGO and PLHIV community.

groups. Even the very coming to focus group does not guarantee participation. In one of the focus groups, one younger participant left the group due to the fact that the interview was recorded. The reason for his distrust may be due to his short experience of living with HIV, and the fact that he was not very familiar with other group participants.

One possible reason why PLHIV do not want to participate in research may be that in a highly stigmatizing setting, like Serbian society is, PLHIV tend to avoid situations in which their status will be revealed and where they will be associated with organizations that are active in the HIV field. Studies have shown that PLHIV tend to keep their status secret in the wider community. For that reason, they are difficult to find and in various studies the participants represent the same group of PLHIV. In addition, the Imperial College study found that some PLHIV are not willing to participate due to their disappointment in activities of some NGOs and GOs as well as suspicion about sustainability of NGOs projects.

It also seems that the reluctance of PLHIV to participate in research is associated with a lack of understanding of the research context and the role they may play in combating the epidemic. Many PLHIV do not understand that their participation may contribute to a positive change in responding to HIV.

Most members of these focus groups are engaged in two associations of PLHIV (AID+ and Q Club), and the Expert Centre has already established cooperation with them. PLHIV recruitment was made through their organizations' representatives. This recruitment method was deemed the most appropriate due to previously established relationships, keeping in mind time constraints as well as limited material resources and common activities prospective.<sup>13</sup> In comparison, the Imperial College study used a broader range of recruitment possibilities (snowballing, NGO referral, and an announcement in the waiting room at the Clinic for Infective Diseases).

However, unlike the current study, the Imperial College research was supported and carried out within the framework of a huge initiative that included a great number of partners (GOs, NGOs, and the Ministry of Health).

In structuring the focus groups, care was taken about group composition based on sexual orientation and drug use, respectively. Stigmatization is strong towards IDUs and MSMs in Serbia,<sup>14</sup> and it seems that stigma bound to these groups exists within the PLHIV community as well. This makes the success of heterogeneous groups impossible, as experience has shown with PLHIV self-help assistance (support) groups, which did not succeed for just this reason. The psychologist from the HIV Clinic also observed that PLHIV feel the need to establish some membership criteria within an association or group.

Recruitment of PLHIV – intravenous drug users, was done via NGO “Veza”, and only these participants were compensated in the form of telephone cards. The reason for that is the estimation of the research team that it would be very hard to motivate people to participate without being compensated.

## **Demographic data**

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<sup>13</sup> NGO IAN assisted in foundation and capacity building of AID+, and it assisted Q club in publications translation. The cooperation is continuous.

<sup>14</sup> Strategic marketing (2006): Stigma and discrimination, Belgrade

After the discussion all participants were asked to complete a demographic questionnaire. The IDU group members also filled in an additional part of the questionnaire, which refers to drugs use.

The three non-IDU focus groups totalled 12 participants, nine males and three females. Participant age range was from 20 to 52 years old. Number of years living with HIV ranged from 2.5 to 23, and all participants were using ART therapy. In terms of these data, it is worth mentioning that this research is to do with persons who have experience in living with HIV and developed strategies of coping with the HIV infection. Having in mind that PLHIV who were not associated with an agency or had less experience with HIV (i.e., those who have recently learnt about their HIV status), did not participate in focus groups, the obtained findings should be viewed in the light of mentioned sample characteristics.

Most of the focus group participants were born in a big town (9); three persons were born in a small town. There was a greater number of persons with a college or university degree (8), while four persons had secondary school education. As such, the obtained results should be viewed in consideration of the fact that most of the subjects have college or university level of education and the experience of living in a big town, as well as that all of them have access to ART. In other words, it is possible that PLHIV from smaller towns and with lower educational level have different mental health problems, different choices of disease management strategies, as well as limited possibilities of treatment and acquiring of other kinds of assistance.

In terms of the marital status, four persons identified themselves as single, six persons married or in some kind of relationship, one person widowed, and one divorced. More than a half of the participants were pensioners (9), although two of them were working illegally because of low pension amounts that were not satisfying their needs.<sup>15</sup> Only two persons were employed, one permanently and one part-time. One person was living exclusively by working illegally.

The focus group with PLHIV - IDUs included seven participants, five females and two males. Years of living with HIV in this group ranged from 10 to 23, and ages ranged from 34 to 59 years. All participants had a long-term experience in drug use, with consumption ranging from 10 to 40 years. Four persons in this group were using ART therapy.

All PLHIV from this group were the users of substitution methadone therapy, while 5 persons, apart from methadone therapy use some other drugs (i.e. marijuana, heroine, ecstasy). All participants were born in a big town and five had college or university degrees while two had secondary school education. All participants reported that frequency and amount of drug use depended primarily on mental condition or mood, while one person additionally addressed money as a factor. In this group, three persons were married and a fourth was in a relationship, and one person each was single, widowed, or divorced, respectively. Regarding employment, only one person had a part-time job, three were unemployed, and three were pensioners.

### **Description of discussion course in focus groups**

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<sup>15</sup> In order to acquire the right to disability pension, it is necessary the insured person be pronounced as completely disabled to work. Changes of health status must be of permanent nature.

It is a general impression that the focus group participants were open to share their experiences with others, although some of them hesitated in the beginning. The very subject of mental health research is delicate and bears the risk of inducing pathology and ruining the image of normality that people want to keep about themselves. Care was taken about that when questions were being composed and posed. However, it was noticed that some PLHIV tended to minimize problems and difficulties (one participant talked about “mild small depression” for which he/she had addressed the psychiatrist).

The fact that in each focus group there were persons knowing each other from earlier time's greatly facilitated participant's ability to open up and discuss personal and sensitive issues. Some participants pointed out that they felt benefit from sharing experiences within the group. They also see the need for regular gathering of PLHIV and working with professional therapist.

Research results were probably impacted, to a certain extent, by participants all belonging to one association (NGO AID + or Q club), and by previously established relationships among the participants. Belonging to the same organization improves cohesiveness within the focus group, but also narrows the wider range of participant viewpoints that would exist in a group made up of representatives from various organizations.

Moderator impressions of these two groups (NGO AID + and Q club), were diametric opposites of the same continuum. The first group, comprised of Aid+ members, was characterized by a positive group atmosphere, trust in the focus group organizers, and a pronounced need to respond to questions and requests in order that together they reach the focus group goal. The members also expressed interest in participating in a group with a therapeutic goal.

On the other side of the continuum, the second group, comprised of Q club members, manifested distrust towards the facilitators, the idea of the group, and the organization itself. This group also demonstrated fear of information abuse, as well as anger that came as a result of being stimulated to think and speak about feelings not understandable to people without HIV (i.e. facilitators, supposing that they are HIV negative). Introduction of a dictaphone and the possibility of data recording created a dilemma in this focus group and brought up issues of (dis)trust and suspicion. The fact that there was a concern because of recording indicates the fear from stigma and distrust. This problem was solved by signing an information based agreement on participation acceptance in the focus group.

It seems that such a wide scale of behaviour and feelings speaks to the fact that anyone living with HIV has felt in some phase of his/her life some of these described extremes, and that, depending on his/her personal structure of problems management, he/she succeeded in making (or is still trying to make) the balance, both within the self and interpersonally. However, it is important to note that although some of participants felt fear and certain distrust, it did not prevent them from understanding the role of facilitators and accept their efforts to approach them.

The group of intravenous drug users differed from the other three PLHIV groups, not comprising drug users, in view of meeting place, number of participants, recruitment method, duration and specific dynamics. The group had a somewhat greater number of participants and a greater number of females than males (5:2) in favour of females. The group moderator was an activist at NGO “Veza”, and a person

with experience in drug use and living with HIV. Facilitation by an IDU living with HIV proved to be very significant, because she was able to initiate discussion using her own experiences, and because of the fact that she knew the participants of the group and had positive relationships with them. Stand-by facilitator in the group was a research coordinator of the HIV, AIDS and mental health Expert Centre. The discussion lasted 2.5 hours. Participants communicated with the moderator and facilitator, but also talked more among themselves, which in certain moments caused discussion spreading and resulted in longer time discussion of this focus group.

### 3. Key Findings

Results obtained in focus groups will be presented here according to topics mostly talked about by PLHIV.

- **Learning about HIV positive status**

Learning about HIV positive status represented a shock for all focus groups participants and it meant the beginning of an adaptation period to new living circumstances. In this period, which for most participants lasted two years, some depressive symptoms occurred, including: insomnia, loss of appetite, anhedonia, decreased feeling of competence and valuation of self, reduced sexual desire, loss of interest for professional aspect of living, and suicidal thoughts. The IDU group also talked about the way the HIV positive result was announced to them, mentioning the non-professional attitude and lack of empathy of the professionals who gave them test result.

- **Increased sensitivity to everyday problems**

Focus group participants outlined their increased vulnerability to everyday problems as an important issue. Almost all of them also agreed that resources for stressful situations management changed and became limited when they discovered their HIV positive status. Experiences of being rejected, loss of social support, fear from disclosing HIV positive status, stressful and sometimes confusing treatment regimens, and facing uncertainty for the own existence, altogether increase the vulnerability to stress PLHIV experience, and affect the ability of stress management.

*“The stress is 100 % more intensive when you are living with HIV. Automatically, you are weaker physically and mentally.”(Male, 46, Belgrade)*

- **Dominant moods: grieving, depression and anxiety**

HIV positive status marked a great change in life and impacted the changed image of self, feelings and people's moods. Grieving is often part of the process after learning of the status, and in some phases grieving may turn into depression. According to these research results, depressive moods are particularly dominant in periods after learning about the HIV positive status and in the beginning of new phases of disease (e.g., when starting with the ART). Anxiety and concern also occur as consequences of uncertainty in view of health, possibility of employment, and foundation of a family. It seems that most participants experienced depressive mood and anxiety jointly, and that these difficulties present basic problems to the mental health of PLHIV.

- **Stigma and discrimination**

One of most frequently mentioned stressors for PLHIV is stigma and discrimination, causing chronic suffering and feelings of isolation. HIV related stigma presents a great load for PLHIV in everyday life. It occurs at many levels, from the family to governmental institutions, and represents a significant determinant of social isolation, fear from others' reactions and the need for keeping HIV status secret. Stigma is the main reason for PLHIV to keep the status secret, because they want to

avoid unpleasant and hurtful situations. Dilemmas such as whether they might or are obliged to disclose their HIV status, particularly to medical workers, present an everyday concern for PLHIV. Many of them have had negative experiences in being refused medical assistance due to the fact that they were HIV positive, which increased their fear and uncertainty in terms of treatment and accessibility to services they might need in future.

- **HIV status as a secret and problem of disclosing**

In many participants there is a need to keep their status secret. The issue of disclosing their HIV status presented an upsetting experience for all participants when they were in a situation to anticipate various losses such as support of friends, family, or a job. However, there is also a need to share a «secret» with others and PLHIV manage this situation in different ways. Some share the «secret» with family and friends, considering their support very important, and experiencing it as a protective factor in facing everyday problems. On the other hand, some participants cannot disclose their HIV positive status to even their closest family and friends, either fearing rejection or feeling very cautious in deciding whom they can tell and whom not.

- **HIV positive status and choosing partner**

The dilemma of telling sexual partners about HIV positive status presents an additional burden for PLHIV. The most frequent solution to this problem among the subjects was abstinence, or intercourse with an HIV positive partner. According to participants' experiences, there is an expressed awareness among PLHIV about the needs of protection and telling a sexual partner about their status; therefore, hiding their status is not the way PLHIV maintain their partner/sexual relations.

- **Loss of friends**

Loss of friends who died of AIDS presented another stressful experience for focus groups participants, «reminding» them about uncertainty of their own existence. Each visit to clinic also depresses them, as well as witnessing worsening health conditions of other PLHIV at the clinic.

- **Unemployment**

Most focus groups participants stopped working after learning about HIV status. Reason for that is, most frequently, physical weakness and opportune infections development, which prevent them from continuing activities they practiced until then. An important stressful aspect of living with HIV for some PLHIV is the feeling that they are capable for work but not in the position to work. Second reason for employment termination and retirement is the fear of stigma and discrimination, that is, reactions of the working environment, which results in withdrawing of some PLHIV.

- **Dissatisfaction with hospital condition**

For PLHIV, the appearance of the HIV Clinic and its technical equipment reflect the perceived level of care the state has for them. Dissatisfied by technical equipment of the clinic and its unhygienic conditions, all participants agree that a better equipped

clinic would induce less negative feelings. In addition, continuous uncertainty regarding treatment availability causes discomfort and anxiety. The question of what to do in case medicaments are unavailable is the constant source of PLHIV fear, and it impacts the person's feeling of control over the virus.

- **Compliance and side effects of ART**

Introduction of ART therapy and ART compliance represent a skill to be managed. Participants understand the significance of complying with the ART, but regularly taking medicaments sometimes presents difficulties in everyday functioning. Furthermore, ART treatments have various negative side effects and require enduring different pains and discomfort. On the other hand, reverse effects have not been recorded in this study (i.e., mental health problems do not impact treatment compliance).

- **Problem management strategies utilized by PLHIV and particularly IDUs**

PLHIV use various strategies to manage problems they are faced with, such as: moving away from and avoiding, comparison with others in the same situation, asking for information and support, self-encouragement, emotional outpours, and acceptance with resignation. Focus group participants also use proactive problem focused strategies, like participation in activities of organizations gathering PLHIV, compliance to therapy, and less risky sexual behaviour.

- **Problem management resources**

Almost everybody in the focus groups agreed that after learning about HIV positive status, resources available to manage stressful situations changed and became limited. However, social support, accessibility to services, optimism and conviction that they could control the disease were classified as very important sources of overcoming problems. All participants told about how important the support of family and friends is for them. The feeling that they are accepted and supported is an important source of energy (strength) necessary for managing everyday troubles. The support of other PLHIV was also mentioned as very important. However, PLHIV differ in view of how satisfied they are with the support given. One person either experienced rejection from friends and family or hides his HIV status and is not supported by his close family and friends. Other PLHIV have had positive experiences and they outlined the role of the family as a source of strength and protection from stressful circumstances. Access to mental health services was limited to the psychologist in the HIV Clinic, who greatly helped some PLHIV and their families. Imprisoned PLHIV have quite limited resources of problem management.

- **Information about the therapy**

Almost half of the IDU group participants were not taking ART, either believing that it is a kind of «experiment» that has not been well examined yet, or fearing that the therapy will not always be accessible and free of charge. Besides being poorly informed about the significance of the therapy, confusion was also notable among the participants regarding the harmfulness and benefits of therapy discontinuation. Although some of them were advised to discontinue the therapy for a period of time in

order to «relax» their organism, opinions exist that the therapy should not be discontinued.

- **Access to mental health services**

Professionals from the HIV Centre present a significant source of support and safety for PLHIV. They understand the needs of PLHIV, and their attitude towards their patients is not discriminating. However, many PLHIV consider the capacities of the Centre limited, in terms of the small number of doctors and psychologists compared to the larger number of patients. Psychological support has been estimated by both PLHIV and the Centre psychologist as important, but insufficient in response to the need of the great number of patients. Very rarely, or not at all, PLHIV ask for psychological support at other places.

- **Mental health of imprisoned PLHIV**

Due to the complexity of the situation of HIV positive prisoners are in, they are exposed to higher risk in terms of mental health problems. They had often faced previous multiple problems in each area of their lives - social, emotional, and physical. According to the psychologist working in Special Prison Hospital, PLHIV prisoners are usually depressed because of the already existing vulnerability (often referring to a death of important persons) and their drug use history. Also, some prisoners are constantly afraid or are apathetic and they ask for much more attention than is available in the hospital. So, this fact accompanied with constrained living condition in prison further worsens the PLHIV prisoners psychologically and physically.

## 4. Discussion

HIV infection is connected with a wide range of mental health problems, including understandable emotional reactions to receiving a diagnosis of a potentially fatal disease and the significant degree of stigma related to it. Beyond emotional reactions, HIV infection is also linked to psychiatric disturbances like depression and neuropsychiatry syndromes, such as AIDS dementia. Understandable emotional reactions, like distress, shock, anger and grieving are very frequent and should not be viewed as abnormal, except in cases in which they take serious and permanent forms and impact the living and social adaptation of persons. It seems that despite the social problems they are faced with, most people successfully cope with the effects of infection, through engaging personal and external resources in order to manage difficulties and prevent development of mental disturbances. In general, literature tells about slight differences existing between seropositive and seronegative people and that most PLHIV adequately cope with the disease most of the time.<sup>16</sup>

In this section, the results will be considered within the context of HIV infection as a crisis. In the first place, approach to HIV as a crisis is identical to treatment of this disease as a chronic disease which implies adaptations to numerous changes and stress. Also, this approach is recognizing specific circumstances that make HIV different from other chronic diseases, like the fact that HIV is sexually transmissible infection, that it is still related to socially stigmatized and marginalized behaviours. Because of that, PLHIV face certain number of additional stressors, like stigma and discrimination, or sexual rejection. Intensive stigma and discrimination may create a lack of support network for PLHIV, which might increase the occurrence of mental health problems.

### 4.1 Vulnerability to stress

Based on results obtained, it may be concluded that transitional changes of mood are frequent with PLHIV, and that these moods are conditioned by living stressors that affect their living quality and mental health. Periods of psychological confusion come in moments of crisis, like learning about the diagnosis, introduction of therapy, HIV-related hospitalization and other stressful transitions.<sup>17</sup>

- **Discovering HIV positive status**

When participants discover their HIV positive status they often have a sudden and enormous change of meaning in their lives. In this period participant experienced significant mood changes.

As said by one participant:

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<sup>16</sup> Catalan J. (1999): *Mental Health and HIV Infection: Psychological and Psychiatric Aspects*, UCL Press, London

<sup>17</sup> Green G., Sobo E.J. (2000): *The Endangered Self: Managing the Social Risk of HIV*, Routledge, London

*»In the beginning, depression was dominant, it's unbelievable despair and question what I'm going to do».* (Male, 41 years old, Belgrade)

In this period, which for most of them lasted about two years, participants say that they were desperate, confused, frightened – as one participant says, feelings ranged from permanent fear to complete insanity. In this period, other depressive symptoms also occurred:

1. Insomnia
2. Sexual desire reduction
3. Anhedonia – feeling of decreased enjoyment of activities  
*»It is not important any more to go to the cinema or theatre; it is not what you need in your life any more»* (Male, 46 years old, Belgrade)
4. Reduced feelings of competence and self-confidence, as well as a changed valuation of self. One participant's words illustrate such feelings best:  
*«When I see myself in the mirror, I see a distorted picture of me, everything that was normal yesterday, is not normal any more, you think about every move, act, relation towards others ...»* (Male, 40 years old, Belgrade)
5. Suicidal thoughts-two participants said that they tried to kill themselves by intensified drugs use. One participant from another focus group told about his thinking to commit suicide:

*»Moments of helplessness are the worst ones... once, I thought to take a sedative which, in combination with ART would provoke a comma, and I thought it would be good for me not to wake up any more».* (Male, 35 years old, Belgrade)

Other participants did not mention suicidal thoughts. To them, it seems as if this indicator presents most recognizable sign of mental problems and the sign of double stigmatization. In view of this issue, one participant (Female, 41 years old, Belgrade) responds to the leader:

*»Do not view HIV as if it is something that's permanently bad. We have bad phases, but it is not due to HIV only».* (Female, 40, Belgrade)

Suicide is also thought about as a coping mechanism, the way to help in surmounting the pain, and as a final solution:

*»In my opinion, suicide is the way to get out of the disease, I am very much afraid of the disease...»* (Female, 29 years old, Belgrade)

6. Loss of interest in professional aspects of living: one participant said that after learning about his HIV positive status, he lost the desire to work, although he was capable of working.
7. Drugs use: People who were using drugs continued with drug use, some of them increasing the quantity of drugs or tablets.

It is interesting to note that in the focus group comprising drug users, participants first talked about the way they discovered their HIV status. Namely, participants stated that results were given to them in a non-professional way, particularly outlining that they were bothered by lack of sympathy of the doctor and the pessimistic forecasts given to them in terms of the life-time left. As told by one participant (Male, 41 years old, Belgrade):

*»Doctor told me that he was sorry, because I was young and I hadn't experience much of life. And at that moment I didn't feel self-sympathy».*

A possible explanation for why drug users mostly talk about the experience of learning about their HIV status may be the fact that drug users are doubly stigmatized and have experienced prior discrimination, making them more vulnerable to stigmatizing experiences. One participant said (Female, 28 years old, Belgrade):

*“When the nurse gave me HIV positive result I started to cry. She asked me: “Why are you crying, you could expect this, you are junky and you know that your boyfriend is HIV positive”. I wanted to die”.*

Most participants of our research learnt about having HIV when the symptoms occurred, and that fact certainly impacted intensity and duration of psychological distress, after discovering of the status. In terms of psychological disturbances and development of vulnerabilities, it seems important to take into account the time of HIV status discovering. After the discovering of HIV positive status, most persons are in a state of psychological distress of moderate intensity and limited duration. At higher risk of developing mental disturbances are those who discovered their HIV positive status at the onset of symptom manifestation. Learning of HIV status at this point in the disease happens relatively frequently, particularly when HIV was transmitted in a heterosexual way. The fact that most persons learn about their HIV diagnosis directly prior to, or at the onset of the symptomatic stage of the disease, as shown by our experiences, adds to vulnerability for psychological disturbances. Namely, in such cases, the time of adjustment provided by the asymptomatic period is short, and for many PLHIV that time is very significant for them to accept the diagnosis, redefine priorities, and make life decisions.<sup>18</sup>

Increased sensibility to everyday problems after learning about the status is something that the focus group participants emphasized as important. Almost all of them agree that the resources for stressful situations management have changed and became limited, or as said by one participant (Male, 40 years old, Belgrade):

*”As soon as you become HIV positive, you become hypersensitive up to ten times more than earlier ... you are constantly under stress, small things may be trigger bad feelings”.*

Besides learning about HIV positive status, there are aspects of living with HIV that induce significant emotional stress that PLHIV perceive as remarkable stressors. These include the issue of status disclosing, particularly in the context of partnership, loss of friends, loss of job, stigma and discrimination, uncertainty of therapy and carelessness on the state level, compliance, and managing of therapy side effects.

- **Disclosing HIV positive status – yes or no?**

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<sup>18</sup> Catalan. J (1999):Mental Health and HIV Infection :Psychological and Psychiatric Aspects, UCL Press, London

“*Living with HIV is living underground...*” – are the words of one participant (Male, 52 years old, Belgrade), illustrating PLHIV feelings and need to keep HIV positive status secret from other people. HIV status is kept as a secret, which has a protective function – protection from rejection and stigmatization. Secret duration is based on fears, guilt and shame, and disclosing secrets within a family or wider environment carries a risk of ruining relationships, ending communication, and discrimination. One significant aspect of HIV as a secret is isolation, which prevents HIV persons from getting necessary professional assistance and social network assistance.

PLHIV recognize the need for support, especially from family and friends. PLHIV satisfy the simultaneous need to tell others about HIV positive status, but also the fear of telling, in different ways. Some of them share the secret with family and friends, estimating their support as very significant, experiencing it as a protective factor in facing everyday problems. As one participant says (Male, 40 years old, Belgrade):

*”My friends, who behave as nothing has happened, help me most...every negativism and rejection upset you thoroughly”.*

- **HIV as a secret and choosing a partner**

The dilemma in terms of disclosing HIV positive status to sexual partners presents an additional burden for PLHIV. While some of them think that *»AIDS is not the primary item in [their] CV«* and that it is not necessary to tell that immediately, others do not agree and think that it should be told in the beginning, in order not to hurt the other person. It seems that the difference in such attitudes partly stems from more intensive or less intensive feelings of guilt and the person’s attitude to HIV. As one participant observed, it is very important to know that you have not infected anyone, *»That you may face anybody and say I’ve got HIV, so what?»*

In regard to attitude about HIV and feelings of guilt, it is also interesting to mention the experience of the psychologist of the HIV Clinic that positive persons in discordant partnerships tend to assume all responsibility and they think that they alone should do anything they can to improve the relationship.

HIV status has impact in terms of limited number of partners, as well. For focus groups participants, discordant pairs represent an ideal to be gravitated towards, but in practice, it is considered hard to reach because there is always a risk of infecting somebody and that very fact generates fear of being close with somebody. What reality presents for these people is abstinence, or intercourse with HIV positive partners. In relationship with HIV positive partners, PLHIV feel more supported and accepted because they think that only an HIV positive person could really understand them:

*“The worst thing is when your partner does not understand you. Somebody should be very, very flexible and open minded to understand living with HIV.”*(Male, 46, Belgrade)

According to participants experiences, among PLHIV there is expressed awareness about the need for protection and telling sexual partners about their status, What is very important is that experiences of PLHIV who had HIV negative sexual

partners who were aware of the HIV positive status of their partner had great impact on their acceptance of themselves as an HIV positive person. Those PLHIV felt much more supported and this positively influenced their quality of life:

*“I did not make pressure to the person when I met him. I knew that he was HIV negative and I told him immediately my HIV positive status. I did not expect to be understood and accepted but he wanted to be in relationship with me. We had sex without any fear or anxiety. I felt like a person, I felt loved, respected and accepted. That was very important for me and helps me to manage with bad feelings. I learned how helpful for me could be disclosure of my HIV positive status”.* (Male, 40 years, Belgrade)

PLHIV who were also IDUs focused on partnership relations in the discussion, considering them very important for self-acceptance and self-respect, and they outlined the significance of the possibility of choice. All participants agreed that a partner should be told about HIV status and responsibility shared with somebody. However, there is a dilemma about the choice of a partner, keeping in mind HIV status. Although they think that it is not necessary to have an HIV positive partner, the dynamics of relationships with discordant pairs is specific. In such relationships, HIV positive partner generally feels as a «lower being» due to his/her status, and as observed by one participant (Female, 34 years old, Belgrade):

*»Feeling of guilt is always raised, the most important criterion of relationship is HIV status, and it justifies everything, that you bear the guilt...».*

On the other hand, one participant states that even pairs in which both partners are HIV positive do not always succeed, and that in such relationships there are too many problems, too much helplessness and « *too much of the same story at one place*».

- **Loss of friends**

The loss of friends who died from AIDS and the anticipation of their own health loss were equally significant stressors for focus group participants. For many PLHIV, the very visit to HIV Clinic has a negative effect, reminding them about the uncertainty of their own existence as well as worsening health of other PLHIV at the Clinic. One participant describes the stressful characteristic of such situations (Male, 52 years old, Belgrade):

*“If something happens to somebody who is in the hospital (worsen health condition), all sorts of things come into my mind.”*

The fact that PLHIV are surrounded by people who have reached the last phase of disease or died reasonably provokes the feelings of distress, sorrow, depression, anger and helplessness. A person may be flooded with despair and hopelessness, so he/she withdraws and loses hope for a quality life. On the other hand, some people may be pervaded with a feeling of life preciousness, and will then try to experience as much as possible and use their opportunities. Others become so depressed that they are not able to reach goals they consider important. For most PLHIV the combination

of such reactions is characteristic and various moods are dominant in certain periods.<sup>19</sup> Watching friends who become affected and die from AIDS also impacts other people to face the reality of their own death, particularly if they also have HIV or AIDS. Not a single focus group participant speaks explicitly about their fear of death, but what appears to be common is the feeling of uncertainty in regards to their health and reduced optimism concerning their future. It is difficult to overcome loss, even when physical health is perfect. People reacting to loss are in a state of crisis, which induces emotional disorganization and helplessness. After a person receives an HIV diagnosis, often multiple losses occur in relatively short period, which causes persons to become overwhelmed with emotions and feel that their life is completely out of their control.

As one participant explains (Female, 40 years old, Belgrade):

*“When people around me started dying from AIDS, I started losing faith in a cure; I gave up everything and started using drugs again. I thought – what now, I’ll die in any case”.*

- **Unemployment and job loss**

Most of focus groups participants stopped working after learning about their HIV status. The reason for that is that the majority of them discovered HIV positive status when they had clear symptoms of AIDS, like physical weakness or the development of opportunistic infections like cytomegalovirus which, in most cases, prevents them from continuing with activities they practiced until then. One participant says (Male, 23 years old, Belgrade):

*“Due to my blindness, I cannot find normal job that I would like to work, that is, I cannot find any job. It makes me nervous because my eyesight restrains me in everything“*

The feeling that they have the capacity to work, but are not in a position to work is a significant stressing aspect of living with HIV for some PLHIV. Another reason for termination of employment and retirement of some PLHIV is their fear of stigma and discrimination within the working environment. The fear from reactions of others in the workplace results in PLHIV withdrawing. As told by one participant (Female, IDU, 34 years old, Belgrade):

*“Generally speaking, people wouldn't face you and tell “I don't want you to work here”; instead they tell you, for example, you needn't make coffee any more, although there was always fuss about who would make coffee; or some new rules are introduced, like, for example, everybody brings his/her own towel, etc, Then you*

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<sup>19</sup> Shernoff M. (1992): Loss and AIDS, People With AIDS Coalition News line, No.75

*realize that it's a stupid situation and that you don't want to be the subject of gossip behind your back”.*

It seems that due to employment termination, PLHIV additionally isolate themselves from the HIV negative environment and look for friends among PLHIV.

Some side effects of ART also impact the change of professional engagement. One participant talks about lypo-dystrophy, which prevented him from doing the job he had before, in which physical appearance was significant. Since professional life represents a significant determinant of quality of life and general satisfaction, job loss for these participants marked a period of adaptation to changed living circumstances.

- **Stigma and discrimination**

Stigma is described as a dynamic process of devaluation (loss of value), which “greatly discredits a person in eyes of other people”.<sup>20</sup> HIV related stigma often induces social isolation and in some PLHIV provokes anger. There is a wish to explain to others what HIV is and how it is transmitted, tied to awareness that it is very difficult to impact others. One participant says (Male, 46 years old, Belgrade):

*“I experienced brutal reactions at work, like, for example, when they move away from me when I pass. Then I wish to tell them everything, but also to run away, to hide from everything”.*

Stigma also causes chronic suffering:” *I feel sorrow permanently, not periodically. I succeeded in building a positive surface, but regardless of what you suppress, you always know where you belong”*, says one participant, who has been living with HIV for 10 years (Male, 52 years old, Belgrade).Or, according to another participant (Male, 40 years old, Belgrade):

*“Discrimination generates the feeling like you are non-stop hitting the wall. I wonder if I may tell my dentist or somebody else”.*

Research comprised of people living with HIV indicates that stigmatization in public may endanger one's identity (Sandstrom 1990) resulting in the loss of self-respect (Siegel and Krauss 1991; Bennett 1990); and that impact is more significant than that of a physical disorder (King 1989; Crowther 1992).<sup>21</sup>

Fear from discrimination limits access to health care beyond the HIV field, which is in accordance with findings of a qualitative study of PLHIV<sup>22</sup>. PLHIV are always

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<sup>20</sup> Goffman E. (1963) Stigma: notes on the management of a spoiled identity. New York: Simon and Schuster, according to UNAIDS (2005) HIV-related stigma, discrimination and human rights violations: case studies of successful programmes

<sup>21</sup> Green G., Sobo E.J. (2000):The Endangered Self: Managing the Social Risk of HIV, Routledge, London

<sup>22</sup> Bernejs, S. , Rouds T., Prodanović, A. (2006): Accessibility, services providing and uncertainty in HIV treatment, Faculty for Hygiene and Tropical Medicine of London University, UK, DFID, HIV

faced with the dilemma of whether to tell a doctor about their status or not. When revealing their status, PLHIV in Serbia were having mainly negative experiences, were sometimes rejected treatment due to their HIV status.

One participant tells (Female, 40 years old, Belgrade): *“It's worst when I go to the dentist and she says that she can't fill my tooth, not because of her, but because of her children. Then I think – what all those charters serve for... it shouldn't be that everyone can become a doctor, it is not enough just to learn the matter, and you should have a personality”*.

In that sense, concern and uncertainty about getting medical assistance burdens PLHIV and induces feelings of uncertainty and anxiety. There is constant concern about how to get the necessary medical assistance when it is indispensable. The experience of the psychologist from the HIV Clinic discussed how the situation of PLHIV is related to how cooperative personnel are within the HIV Clinic are with the medical workers whom are outside the HIV/AIDS field. Namely, the psychologist estimates that cooperation with other medical workers, (for example oncologists) is bad, yet is all the more needed due to the effects of ART therapy. Nevertheless, these non HIV/AIDS medical professionals are not interested in the needs of PLHIV and refuse to come to the HIV Clinic. Cooperation between the psychiatrists and was also estimated as being unsatisfactory by the psychologist. On the other hand, PLHIV do not want to bring charges against doctors because they don't want to arouse the doctors' anger, nor do they want to get publicity.

Almost all participants have had painful experiences of rejection, both by their wider environment and by their family and friends. A typical situation they face is explained by one PLHIV (Male, 46 years old, Belgrade):

*“While I was in a disco-club, I received a message on my cell-phone – “you spread AIDS, and you know that it is punishable by law” ... then I wish to hide away and run away from everything”*.

Discrimination within the family and working environment is especially painful. Words of one PLHIV may illustrate such experience best (Male, 35 years old, Belgrade):

*“My sister delivered a baby almost seven months ago, and I haven't seen that kid yet. I feel they don't want me, they are afraid of me, I can feel their fear. It hurts a human; I am a kind of secret uncle”*.

Within the IDU group, stigma was also observed as both HIV and drug related, as illustrated by the experience of one participant (Female, 45 years old, Belgrade):

*“When I asked the doctor about the HIV test result, he responded shortly and clearly – you drug-addicts are all positive...”*

This is characteristic of the multi-layered structure of HIV stigma; intensifying negative connotations by relating HIV and AIDS to already marginalized behaviours like drug use or homosexual behaviour, respectively.<sup>23</sup> Stigma is more pronounced towards people infected through sexual intercourses or drug use, because such behaviours are considered to be under a person's control, so such person should "blame him/herself" for the infection. Stigma is often related to "chosen" living styles of infected population or belonging to race or ethnic minority. For that reason, males having sex with males and IDU are more frequently stigmatized, unlike people who did not acquire the virus by a chosen activity (e.g., haemophilia patients or children of HIV positive women are viewed as innocent) (Herek, 1990, according to HOPE, 2006)<sup>24</sup>.

As shown in the research of Strategic marketing on stigma and discrimination towards marginalized population in Serbia<sup>25</sup>, the following percentage of the population of Belgrade considers the certain behaviours to be unacceptable, namely: aggressive behaviour and violence (90%), theft (90%), narcotics using (87%), corruption (84%), prostitution (76%), and then homosexual orientation (63%) and alcohol consuming (61%). Such results show that belonging to marginalized (drug-addicts) group, besides HIV positive status, may also make access to health care and treatment by medical workers and getting necessary assistance more difficult.

Therefore, stigma is evident on many levels, from family to governmental institutions, and represents a significant determinant of social isolation, fear from reactions of others and the need to keep HIV status secret. Stigma and discrimination keep PLHIV on the outskirts of society, which influences their health seeking behaviour and makes them additionally vulnerable to stress, anxiety and depression.

- **Uncertainty of therapy and care on governmental level**

The appearance of the HIV Clinic and its technical equipment present significant determinants of optimism towards the future, and are also a reflection of care on the governmental level for PLHIV. Dissatisfied towards the technical equipment at the HIV Clinic, all participants agree that better an equipped Clinic would generate less negative feelings. Mood evident in the waiting room of the Clinic is well illustrated by the observation of one member of the Expert Centre (IAN staff, after the visit to the Clinic for Infective Diseases):

*"I have never been in the waiting room which was so quiet, like the waiting room of the Clinic for Infective Diseases office. Nobody talked to anybody, nobody looked each other".*

Not only has that, but continual uncertainty in terms of availability of therapy and medicaments induced discomfort and anxiety in PLHIV. They question what would happen if the medicaments were not available, and this is a constant source of anxiety

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<sup>23</sup> UNAIDS (2005) HIV-related stigma, discrimination and human rights violations: case studies of successful programmes

<sup>24</sup> HOPE Program Training Resource Package (2006)

<sup>25</sup> Strategic marketing (2006):Stigma and discrimination,Belgrade

and fear that impacts the feeling of control for people who have HIV/AIDS. As seen from the observation of one participant (Male, 52 years old, Belgrade):

*“Without therapy, I would be broken down in psychological terms”.*

Such statements emphasize the significance of therapy being continuously available if HIV is to be perceived as a chronic yet manageable disease. As confirmed by findings of the qualitative study, availability of therapy and information about it is an important source of safety for many PLHIV, as is trust in governmental institutions.<sup>26</sup>

- **Therapy compliance and managing the side-effects of therapy**

How ART therapy is introduced and issues of compliance with ART therapy are skills that could be better addressed in health care system. Participants understand the significance of compliance with ART but regular use of medicaments is sometimes difficult in everyday functioning. Additionally, ART has various negative effects, as participants must endure various pains. As mentioned by one PLHIV (Male, 41 years old, Belgrade):

*“I suffer from polyneuropathy, kidney stone, lypodistrophy, and I know that this is the result of the therapy, but what can I do...”*

A female participant explains that it is difficult for her to comply with the therapy because of the large quantity of various medicaments she had to take, which includes ART, methadone, antidepressants. Two other participants, who take ART, point out how important it is to use the therapy, as well as the need for better information about what the side effects of the medicaments are and how to alleviate pain and discomfort caused by the therapy. Namely, due to the strong negative side-effects of ART, these participants would discontinue the therapy in order to take a break and rest. Participants in the discussion emphasized the significance of exchanging and communicating experiences between the therapy administration and among other PLHIV.

- **Information about the therapy**

In the focus group discussion with PLHIV who have experiences with injecting drugs, there was a notable problem of being insufficiently informed about ART. Half of the participants do not take ART, either thinking that it is a kind of experiment that has not been explored enough or for fear that the therapy will not be always available or free of charge. Besides being badly informed about the significance of the therapy, there was also notable confusion among the participants related to whether or not the discontinuation of ART therapy was harmful or useful. Although some of the participants had been advised to discontinue the therapy in order to “rest” their

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<sup>26</sup> Bernejs, S., Rouds T., Prodanović, A. (2006): Accessibility, services providing and uncertainty in HIV treatment, Faculty for Hygiene and Tropical Medicine of London University, UK, DFID, HIV Prevention among Vulnerable Groups Initiative, United Nations Development Programme, Belgrade/Podgorica

organism, there were other opinions amongst the group that the therapy should not be discontinued. As stated in the qualitative study of PLHIV, professionals in Serbia do not consider therapy discontinuation to have a significantly harmful effect on patients' health. However, due to the existing problems with monitoring test supplies, the effect of therapy discontinuation has not been thoroughly examined, whereas in other relevant studies a negative impact was found to exist.<sup>27</sup>

It is very difficult for a person who has not been living with HIV and also has problems with status disclosure to get accurate and complete information about the therapy he or she is taking. Often PLHIV have a limited choice of information sources and they are not always able to obtain full information in an acceptable form from the doctor who prescribed the therapy. One focus group participant (Male, 30 years old, Belgrade) said:

*“Doctor is a great expert but I did not understand a word when he was talking about lypodistrophy, neuropathy and therefore I visited the site and saw pictures of disease which scared me a lot. I mainly get informed through the Internet and I have noticed that not all of the sites on HIV are friendly”.*<sup>28</sup>

HIV positive status creates significant changes in life, which often includes an adjustment of self-image. Living with HIV implies adaptation to various new situations and challenges. As told by one participant (Male, 20 years living with HIV, Belgrade)

*”Living with this disease is an art; your entire life is changed from the root.”*

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<sup>27</sup> Bernejs, S. , Rouds T., Prodanovic, A.; Accessibility, services providing and uncertainty in HIV treatment, Faculty for Hygiene and Tropical Medicine of London University, UK, DFID, HIV Prevention among Vulnerable Groups Initiative, United Nations Development Programme, Belgrade/Podgorica, 2006

<sup>28</sup> Lypodistrophy: irregular fat distribution

Neuropathy: Peripheral neuropathy (PN) is a disease of the peripheral nerves. PN can be a minor nuisance or a disabling weakness. It usually involves a feeling of pins and needles, burning, stiffness, or numbness in the feet and toes. It can also be tickling sensations, unexplained pain, or sensations that seem more intense than normal. PN symptoms can come and go. Serious PN can cause difficulty walking or standing.

## 4.2 Grieving, depression and anxiety

The division between “we” and “you” is a source of permanent grieving, feelings of isolation, and being special in relation to others. Some PLHIV experience anger and animosity to their own environment:

*”People cannot understand how PLHIV feel, nobody understands you, and you haven't got a real friend with this disease”* (Male, 41 years old, Belgrade).

On the other hand, grieving may transform into depression in certain phases and, as shown by the research results, there are two especially sensitive periods for this: first learning about the status and during the beginning of a new phase of the disease, like starting with ART. The occurrence of new symptoms, as well as beginning ART therapy, may trigger depression and maladaptive coping strategies. One participant reported about that (Male, 40 years old, Belgrade): *“In the beginning of my therapy I was addicted to tablets, although I hadn't been a tablet-addict”*.

Besides depressive symptoms such as sleep disorders, appetite change, reduced libido, and feelings of helplessness, some participants stated that periodically they are overwhelmed with fear and anxiety when thinking about their future and prospects.

The statement of one participant is quite illustrative (Female, 29 years old, Belgrade): *“Sometimes I feel completely chaotic and it entirely ruins my ability to organize, plan and invest in the future”*.

Anxiety and concern come as the result of uncertainty in regards to health, employment and the foundation of a family. Uncertainty regarding medicaments and monitoring tests as well as dependence on the state are other sources anxiety and worry for PLHIV.

Another anxiety-producing dilemma is the uncertainty of what symptoms are caused by HIV and what symptoms are from something else? Any changes in physical appearance generate concern about whether HIV has progressed. For instance, one participant stated that the frequent occurrence of her hair looking dirty caused her to ask her doctor for advice, since she thought it was related to HIV.

Side-effects of the therapy, particularly lypodistrophy which causes visible changes in appearance, evoked anxiety and depression in patients. Lypodistrophy impacts the change of perception of one's own attraction and appeal, and for PLHIV this is a painful process.

The psychologist from the HIV Clinic observes that there may be various mental disorders encountered in PLHIV that can also be found in the general population, ranging from customary reactions of adaptation to HIV positive status to more serious disorders. However, she points out that a common phenomenon for most PLHIV is low self-respect and feeling less self-value. Such feelings are induced by rejection and non-acceptance by their environment, resulting in the belief that they are of less worth. According to her, it is common for PLHIV to have an unrecognized fear of death. Based on her opinion, the reason of such fear lies in the fact that many PLHIV have not yet “processed” information about the effectiveness of existing therapy, and so they do not realize that situation for HIV positive persons is much better today

regarding treatment than it was when the HIV epidemic first began. Therefore, when they discover their HIV status, their fear of death is manifested in their fear of the future and lack of perspective.

It seems that most participants have experienced depressive mood and anxiety jointly, and this presents difficulties in basic PLHIV mental health problems. Similarly, there a doctor from Institute for Drug Addiction who thinks that PLHIV mental health problems are based on “depression syndrome”.

### **4.3 Connection of mental problems and ART adherence**

Participants reported that they had problems induced by ART, including changes in sleep, balance, vision, anxiety, hypersensitivity and feelings of confusion. All participants agreed that taking these medicaments lead to various mental conditions-“from depression to hysterical condition“. Such a variety of side-effects may endanger therapy compliance, as mentioned by one participant (Male, 40 years old, Belgrade):

*“It was hard, I thought I couldn’t stand it any more, but I have always been optimistic“*

Sleep disturbances in particular are pointed out by participants as an ART induced consequence. They describe their dreams “as if happening in reality”, due to the hallucinogenic effects of some medicaments. Mood changes induced by the ART therapy are also difficult to cope with. One participant explained the change of his mood when he first started taking the therapy (Male, 42 years old, Belgrade):

*“It was one schizophrenic situation, I smashed everything at home, and I quarrelled with my friends...”*

All participants agree that their moods do not affect whether or not they take ART and that they regularly take the therapy as advised by doctors. The fact should be taken into account that participants in this research who do take ART are very aware of how indispensable ART therapy taking is, and that they generally implement constructive mechanisms for overcoming problems.

### **4.4 Coping Strategies**

The perception of HIV/AIDS as a chronic disease, in turn, focuses attention on how to cope with stressors related to the disease. PLHIV, as mentioned, face many stressors: negative reactions from their environment, anxiety and fear about what therapy will be available, personal fears about death, and anticipation of bodily and mental decay. In order to overcome the chronic stress they experience, PLHIV use different strategies.

- ***Moving away from, avoiding***

This coping mechanism of avoidance was notable in two participants. One PLHIV's words illustrate this management strategy best (Female, 29 years old, Belgrade):

*“When I feel bad, I am in a mood to suppress, not to think about it, not to come in touch with such topics.”*

- ***Comparison***

Comparing their situation with other people whose situation is more difficult than theirs is also a mechanism which serves to maintain optimism and hope. As one PLHIV put it (Male, 45 years old, Belgrade):

*“When I feel bad I remember that there are people who feel worst than me. That helps me sometimes”.*

- ***Asking for information and support***

Gathering information and knowledge about the disease is also a significant way for PLHIV to regain control over their lives. In that regard it may be noted that all PLHIV participating in this study were very knowledgeable about the therapy, medicaments, and the side-effects of therapy. The experiences of other PLHIV and their support are very important, as is advice from personnel at the HIV Clinic. As one participant said (Female, 27 years old, Belgrade):

*“The psychologist from the Centre helped me and my family a lot, in the first place by giving concrete advice – how my parents should behave towards me and my disease”.*

Support and exchange of experiences with other PLHIV are also significant for overcoming emotional crises as was illustrated by one participant (Male, 45 years old, Belgrade):

*“Experience of others means a lot, they give me concrete pieces of advice, like, for example, when caught by panic, fear – go for a walk, talk to somebody...”*

- ***Self encouragement***

One way emotions were controlled is through the belief that a person is strong and durable enough to overcome their troubles. Some focus group participants use this mechanism in order to encourage themselves, preserve hope and optimism. *“The thing which does not kill you but makes you stronger”* illustrates this management mechanism of some participants. Optimism and relying on hope is also important and helpful to face stress. Optimism of one participant is illustrated through feeling in control and believing in a good future (Male, 23 years old, Belgrade):

*“I am convinced that everything will be O.K. if I comply with the therapy.”*

- ***Emotional outpours***

When they feel strong anxiety, some PLHIV use sedatives, and one female participant tells about emotional tension drain through crying, rage, anger.

- ***Resignated acceptance***

Accepting the disease as something predetermined by fate is a way of externalizing the cause of the disease. This is a management mechanism which one PLHIV applied when discussing how frequently he is faced with social misunderstanding of HIV. He said (Male, 41 years old, Belgrade):

*“And you are the most normal human being who happened to have error in the genetic code and it is not your fault at all”.*

Research has revealed a connection between management mechanisms and psychological distress for people who are living with chronic diseases; there is a positive correlation between the management mechanism of avoiding and depressive moods with negative feelings (Aldwin & Revenson, 1987; Felton, Revenson, & Hinrichsen, 1984; Felton & Revenson, 1984)<sup>29</sup>. Research done on PLHIV found similar results: avoidance was positively related to psychological stress measures, while actively-positive strategies that were more focused on the problem were negatively correlated with psychological stress (Fleishman & Fogel, 1994; Namir, Wolcott, Fawzy, & Alumbaugh, 1990; Wolf et al., 1991)<sup>30</sup>.

Although this research does not enable finding out such relatedness, it is interesting to note that the focus group participants of this research mainly use active approaches while managing the chronic stress they experience. The fact that most of the participants of these focus groups belonged to two associations of HIV positive persons indicates that this research involved participants who use active strategies in stress management because they approached these organizations and have participated in research studies. Of course, this does not mean that persons, who are not involved in work of associations, do not have active management strategies, for there are other parameters of the disease that challenge functional management.

The active approach of stress management and adaptive strategies contribute to the wellbeing of PLHIV, and are classified as follows:

- Activism-engagement in assisting other PLHIV, participation in various organizations, and activism in the HIV/AIDS field were mentioned by many participants as being very significant for PLHIV to feel successful because they are doing something and are thus able to deal with other activities. As told by the psychologist from HIV Clinic: *“People who continue to be active emit good, positive energy”*

- Therapy compliance-all participants agree that there is a strong awareness about the need to take the therapy regularly. As said by one participant, (Male, 41 years old, Belgrade): *“You know that you must take the therapy and there is no dilemma”*. Everybody agreed that not a single moment their mood impacted their therapy taking.

- Reduced risky sexual behaviour-an equally important component of effective management outcome is the reduction of risky sexual behaviour. All participants say

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<sup>29</sup> John A. Fleishman et al.(2000): Coping, Confliction Social Interactions, Social Support, and Mood Among HIV-Infected Persons John A.; American Journal of Community Psychology, Vol. 28

<sup>30</sup> Ibid.

that they regularly use protection, regardless of the mood or alcohol use, and that this attitude was held by other PLHIV as well.

For PLHIV who have had experience injecting drugs there are three coping strategies that dominate:

- ***Emotional outpours***

All participants say that their drug use is intensified when in stressful situations. According to one participant (Female, 40 years old, Belgarde):

*“When I feel bad, in some moments of discrimination, when I realize that I am nobody's niece, it happens that I take drugs, although I was clean before that”.*

Such a mechanism of defence is not constructive; having in mind that it reflects risky behaviour.

- ***Moving away from, avoiding***

It seems that the most illustrative manifestation of this mechanism is not starting with the therapy. Although participants state that the reason for not starting the therapy is their uncertainty about its effect, it actually seems to be a part of HIV status denying mechanism. The participants who are not on any type of HIV medicaments did not have more severe difficulties or worsening of their health condition and this fact certainly affected the occurrence of not taking medications as an avoidance mechanism.

- ***Asking for information and support***

Gathering of information and knowledge about the disease, therapy, and side effects of the therapy were the mechanisms used by some participants. A few of the participants, who were not sufficiently informed either about HIV or the therapy, dominantly use the mechanism of avoiding facing the disease. Participants point out how useful and significant the hearing about experiences of other PLHIV, support of other PLHIV, and counselling with personnel from the HIV Clinic is to them.

How stress is faced and how HIV is adapted to may be classified as those which are less adaptive for the wellbeing of PLHIV. Maladaptive ways of stress management are: continued drug use, intensified use of drugs, and not starting therapy. This was well illustrated by one participant (Male, 59 years old, Belgrade):

*“I continued living as before, since I became HIV positive, I haven't changed anything, I couldn't change anything”.*

Reduced risky behaviour is also an adaptive strategy, as when drug use is reduced and risky behaviour is lessened in order not to infect others or worsen their own condition. Some participants realize the importance of the therapy and comply with it, which also presents a significant component of adjustment to their HIV status.

## 4.5 Coping sources

- ***Support from family members***

All focus group participants discussed how important the support of their family and friends is to them. Feeling accepted and supported are important sources of energy for managing everyday difficulties. What is most beneficial is in “relationships where nothing has changed.” However, PLHIV differ in whether they are satisfied with the support they have received. Those PLHIV who have experienced rejection by family and friends or who hide their HIV status are not supported by their closest friends or family. Other PLHIV have had more positive experiences and emphasize the role their family has played as a source of energy and a feeling of being protected from stressful experiences. The words of one participant, which everyone in the group agreed with, illustrate the importance of the family (Female, 26 years old, Belgrade):

*“It is most important to have family that wouldn't kick you out and reject.”*

The way family treats the member with an HIV positive status greatly depends on the family relations established prior to learning of his or her HIV status. An HIV/AIDS diagnosis presents a significant crisis for a family. The primary task of a family in such situations is to create a new perspective related to the disease occurrence and to maintain competence within the context of partial loss and/or possible death of a family member. The family which has been successful in crises management will likely be more apt to take a functional attitude and response to new circumstances.

According to experiences of the psychologist from the HIV Clinic, a person who supports PLHIV often has the status of a co-therapist. For that reason it is important for PLHIV to work on improving relations with significant persons in order to share their grief and their dissatisfaction with people around them who are also suffering. As told by one participant (Male, 52 years old, Belgrade):

*“It is important to have somebody to share it with, both in professional terms (refers to psychological assistance), and in terms of friendly attitude and health related matters, otherwise, you fall into depression”.*

The research results indicate that some participants are not supported by their family and friends, due to their family's fear, misapprehension and misinformation about HIV.

In the group of IDUs, family was discussed in the context of rejection and discrimination, while only one female participant talked about a positive example of acceptance and support. Most of participants did not mention their family. The reasons for that may be the dysfunctionality or lack of acceptance and support of their family which existed prior to the family learning about their HIV status. As observed by the doctor who works in the Institute for Drug Addiction, families of IDUs are generally incomplete, and often only the mother takes care of a sick family member.

In the IDU group, the support of other HIV positive persons is considered most important. All participants agreed that it is only a HIV positive person who can

understand you and that most people do not have broad enough views to be able to accept and understand you.

- ***Support of PLHIV***

All participants point out that the possibility of exchanging experiences and having social events with other PLHIV are significant. The psychologist from the HIV Clinic observed that PLHIV lack a place of mutual gathering. In that regard, he underlines the necessity of having precise time and place for them to gather, and that some membership criteria should be set like the criteria that exists in homosexual orientation associations or drug users experience exchange associations, because it has been shown that having diversity within groups has not been successful. The reason for a lack of response when attempting to mix homosexual and IDU groups could be that intravenous drug users and homosexuals each represent groups in which stigmatization is most expressed within Serbian society. The Strategic Marketing research which investigated social distance towards marginalized groups for people aged 18-70 found that 80% would not allow drug-addicts to enter their house, and 76% would not allow homosexuals into their house. Three other highly stigmatized groups who would not be allowed to enter the home are as follows: criminals-81%, prostitutes-71% and alcoholics-66%. It seems that stigma related to homosexual orientation and stigma related to IDUs exists for PLHIV too, which prevents heterogenic self-support group for PLHIV.

- ***Self support groups***

There are currently two active PLHIV associations in Belgrade. A reason why less participation of PLHIV in self-support activities and little community support in PLHIV activities could be stress induced by: the lack of supply of HAART therapy, level therapy success, amount of monitoring tests, their doctor's orders and fear of the health protection service, as was indicated by the Qualitative Study of PLHIV.<sup>31</sup> Due to these stressors, there has been reduced self-confidence and feeling of independence for PLHIV, who think that they are not capable of engaging themselves in advocacy in the field of HIV and activities of the community. Not only that, but their engagement is made more difficult because of their fear of discrimination when revealing that they are HIV positive to others.

- ***Accessibility to services***

The key for all the problems PLHIV have is in the HIV Clinic. The clinic is the place where they can receive psychological support, and although this is highly valued, it is considered insufficient. Many patients relate their safety and health to the clinic and in the doctors who work there. The PLHIV participants don't doubt the devotion and skills of the doctors and fully trust them. As stated by one focus group participant, people working at the clinic are the light in the darkness and give hope in

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<sup>31</sup> Bernejs, S. , Rouds T., Prodanović, A. (2006): Accessibility, services providing and uncertainty in HIV treatment, Faculty for Hygiene and Tropical Medicine of London University, UK, DFID, HIV Prevention among Vulnerable Groups Initiative, United Nations Development Programme, Belgrade/Podgorica,

the lives of PLHIV. Although there is no discrimination related to the availability of other mental health services, PLHIV very rarely ask for help at places other than the HIV Clinic. This seems to partly stem from their fear of discrimination in health institutions, and partly from the fact that they are not aware of their own mental problems.

According to Sarah Bernays, who researched the experiences of 42 PLHIV and followed up with them for a year, PLHIV often do not recognize the need for support from professionals in regards to mental health problems, for they do not understand that the problems they face are mental health issues. The system of referring PLHIV to mental health services has followed the principle that the priority for PLHIV is their physical problems. On the occasion of receiving orders from general practitioners, physical health is the primary issue and professionals are not perceived by PLHIV to be trained to treat mental health problems.

At the same time, the focus of PLHIV on physical health prevents them from having an awareness of the mental health problems they are facing. In regards to how professionals treat them on mental health issues, PLHIV emphasize the significance of empathy, having an interest in helping them, and having education in the service improvement of PLHIV mental health.

PLHIV who have experiences with injecting drugs are most connected with the Institute for Drug Addiction Due to Methadone Maintenance Programme. These PLHIV participants estimate the service of this institute as being unsatisfactory, expressing that professionals are insufficiently trained or sensitized to mental health issues surrounding HIV, they lack information about the HAART therapies PLHIV take, and do not devote very much time to PLHIV. However, they also said that employees in the Institute for Drug Addiction did have an indiscriminate attitude towards them, as opposed to other institutions.

- ***Optimism and locus control***

Participants also differ in how much they believe in the fact that outcomes depend on their own behaviour. The perception that HIV is a chronic disease is important to overcome. *“With HIV you can live and with therapy you enjoy”* is the parole mentioned by one participant, pointing out how significant the possibility of control is. Therapy compliance and feeling in control of what happens to them is very important for PLHIV, and may be best illustrated in the case where one PLHIV made stocks of medicaments for months ahead. On the other hand, what makes such optimism deceitful is the lack of confidence in governmental institutions and uncertainty in regards to therapy availability.

Apart from the existence of an internal locus control, social events with PLHIV who are full of life and optimism, where there are attitudes that things will be better; represent a basis for PLHIV to manage their problems. As told by one participant (Male, 35 years old, Belgrade):

*“You should be lucky to meet people so full of life and who believe that they will be better, it helped me more than anything”.*

## 4.6 Mental health of imprisoned PLHIV

Living with HIV in prisons brings differences from other PLHIV in many aspects. First of all, the situation of total isolation influences treatment access and coping strategies of imprisoned PLHIV. Also, PLHIV in prisons are usually IDUs who had a history of mental health problems before they discovered their HIV positive status. Lastly, uncertainty about the future and what will happen when they leave prison is the question that most influences their living condition in prisons. Because of the distinct differences between PLHIV living in prison versus PLHIV who are not, the researchers chose to present the live of PLHIV prisons separately.

### Special Prison Hospital

There are 34 penitentiary institutions in Serbia, including Kosovo<sup>32</sup>. The number of HIV positive prisoners in 2005 was 22<sup>33</sup>. Penitentiary institutions usually have their own health care service and bedside healthcare services in prisons, and there is a institution which specializes in medical treatment of prisoners – the Special Prison Hospital located in Belgrade. In this hospital, persons with acute somatic disorder are treated whereas they can not be treated in the other penitentiary institutions; those who need security measures associated with compulsory psychiatric treatment and those who are in compulsory treatment of alcoholism or drug abuse are in custody at the Special Prison Hospital as well.

In Serbia, diseases like AIDS, hepatitis C and TBC are generally treated in special institutions, such as the Clinic for Infection and Tropical Diseases. According to the Director of Special Prison Hospital, there are significant problems in the high frequency of drug users and infective diseases, like Hepatitis C, Hepatitis B and HIV, among prisoners. In order to improve the quality of life and treatment of PLHIV in prisons, there are some efforts for improving the knowledge of prison staff on these topics. UNDP and OSCE have realized some educations in this regard.

The Ministry of Health supervises the staff's professional competence, while the Ministry of Justice controls the legality of the prison regime. Delegations from the International Red Cross, OSCE, Council of Europe, and other professional organizations from Serbia and abroad regularly visit the Special Prison Hospital.

There are several issues in the Special Prison Hospital that could use improvement. The security service is understaffed and cannot guarantee maximum security to both staff and patients. In the opinion of the head of the service the number of security officers should be increased by 50%.<sup>34</sup> Overcrowding is a major problem and one reason for the lower quality of living and treatment possibilities in the institution. Heating, plumbing and electrical installations are also in need of reconstruction. The rooms accommodating somatic patients need to be redecorated in keeping with the standards of medical treatment. There is not a sufficient number of

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<sup>32</sup> Annual report for 2005, Ministry of Justice, Administration of the Execution of Penitentiary Sanctions, p. 79

<sup>33</sup> Annual report for 2005, Ministry of Justice, Administration of the Execution of Penitentiary Sanctions, p. 65

<sup>34</sup> Prisons in Serbia, April 2005-April 2006, Helsinki Committee for Human rights in Serbia,

<http://www.helsinki.org.yu/doc/reports/eng/Prisons-2005-2006.pdf> p.86

doctors in relation with patients, especially specialists in internal medicine. And, there are no premises for religious ceremonies for the family visits.

According to the report of monitoring team<sup>35</sup>, patients interviewed in the Special Prison Hospital did not complain of the quality and quantity of the meals served to them.

At the moment of Expert Centre visited the hospital there were two prisoners living with HIV, both of whom were in the drug abuse ward. Patients living with HIV/AIDS are not separated from other patients. However, their fellow patients who are in regular contact with them are informed about preventive measures and the nature of this transmissible disease. HIV testing is mandatory. Although two hospital staff members were trained in VCT, the service has not been established.

HIV positive results are given by the Head who is a psychiatrist. The Head informs the team, and then the person with HIV is referred to a psychologist. The psychologist recommends that other prisoners be told about the persons' HIV positive status, in order to maintain safety measures and because there are too many psychopaths and too much violence. Generally speaking, patients have the freedom of not discovering their HIV status. However, treatment and detention of most of them is mandatory - a decision brought on the grounds of clinical observation and examination.

At the drug use ward there are 150 drug users. Two psychologists and two psychiatrists are working here. When talking with the psychiatrist researchers learned that among these ward prisoners two groups can be differentiated: those who "fell into" criminal activity due to addiction and those who were primarily criminals but periodically became involved in drug abuse, avoiding using heroin, and using cocaine or marijuana from time to time). They tend to come to prison hospital because of the better living conditions. Therefore these prisoners present themselves as IDUs with serious drug addiction.

In PLHIV treatment, Special Hospital cooperates with HIV Clinic. PLHIV, accompanied by guards go to Clinic for Infective Diseases for already arranged regular control and doctors as necessary come to the Ward.

### **Mental Health Issues for Imprisoned PLHIV**

Mental health problems of imprisoned PLHIV differ from problems encountered by other PLHIV, in terms of the complexities of their living situation, criminal backgrounds, often dysfunctional families, and lack of resources for problems management due to their specific setting. All of these factors influence the mental health of imprisoned persons so it is difficult to see what mental health problems are specifically related with HIV. Through the interview with the psychologist from the Prison Hospital the researchers found out that learning about and living with HIV in prison should be viewed in the context of all problems that are characteristic for this population, including: social, psychological and health issues. The psychologist notes that the way the prisoners accept their HIV positive status is largely determined by their age and residence. Younger prisoners, as well as those coming from towns

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35 Prisons in Serbia, April 2005-April 2006, Helsinki Committee for Human rights in Serbia,

<http://www.helsinki.org.yu/doc/reports/eng/Prisons-2005-2006.pdf> p.85

outside Belgrade, face bigger problems in adaptation to HIV positive status. This difficulty in adaptation may be explained by the fact that older prisoners have different prospective and expectations for their future compared to the younger ones. Additionally, persons from other towns are probably faced with more extensive prejudices and discrimination in their environment.

A very significant issue in regards to the quality of life for imprisoned PLHIV is the attitude of other prisoners towards them, which tends to be acceptant and non-discriminatory. Interviews with both PLHIV and professionals have revealed that PLHIV in the Special Prison Hospital are not stigmatized and that they feel protected. However, according to Sarah Bernays<sup>36</sup>, it should be taken into account that in other penitentiaries, discrimination exists and that the Special Prison Hospital is an exception. Besides, the experience of researches from Qualitative Study proves that PLHIV are in a privileged position in the Special Prison Hospital in terms of having accessibility to health care and institutionalized treatment. The medical personnel care about PLHIVs' regular therapy taking and compliance with their medicaments. On the other hand, however, there may be negative implications for PLHIV in that responsibility for treatment is reduced after going out of prison. Access to medical care out of prison may actually be more difficult in terms of stigma and discrimination.

Based on the interview with Sara Bernays, who conducted interviews with PLHIV in Special Prison Hospital, problems of imprisoned PLHIV can be divided into three categories:

1. More difficult access to doctors in the hospital

Sometimes it is a problem to inform a doctor when a person has a health problem because patients must access doctors indirectly, through the guards. Prisoners rarely see doctors, particularly at Females Ward. At Males Ward, there are doctors' premises and access to doctors is better.

2. Anxiety due to transfer to other penitentiary or anxiety due to going out of prison

One female subject was anxious on the occasion of her transfer to another prison – because she had fears regarding food, quality of care, access to services and stigma. But it turned out that care quality and access to health services was satisfactory. For two prisoners, being released from prison was stressful, because they were worried about where (or how) to get further treatment and the access to the therapy.

3. Concern about due time supply of the therapy to the hospital

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<sup>36</sup> Bernejs, S., Rouds T., Prodanović, A. (2006): Accessibility, services providing and uncertainty in HIV treatment, Faculty for Hygiene and Tropical Medicine of London University, UK, DFID, HIV Prevention among Vulnerable Groups Initiative, United Nations Development Programme, Beograd/Podgorica

Treatment for prisoners with mental health problems includes accessibility to semi-open group therapy and family therapy once a week for a small number of prisoners. The psychiatrist<sup>37</sup> outlines that there is a great need for an individualized approach to prisoners' mental health, but it is not feasible due to limited capacities of the institution. She also realizes that PLHIV in Special Prison Hospital need more information and contacts with services outside the prison, because when they are released from prison they will not be protected at all. Sarah Bernays believes that it is necessary to provide support for PLHIV after they are released from prison, because PLHIV are not prepared for new living and treatment conditions.

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<sup>37</sup> Information obtained through interview with Special Prison Hospital psychiatrist Milena Stanković

## Case study

Robert is 26 years old Roma who has been in Special Prison Hospital for nine months at the Drug Users Ward. He learned about his HIV positive status on coming to prison, when mandatory tests were done within the scope of other analyses. Besides being HIV positive he is also Hepatitis C positive. He cannot speak Serbian well, because he grew up in Germany. Because he does not have a good grasp of Serbian language, he feels excluded from other prisoners in the hospital.

His first reaction to HIV was a shock. Later he tried to overcome what he learned by not thinking about HIV. After he found out about his HIV status, everything changed for him. What was particularly singled out were thoughts that he would not be able to have family, the fact that he must give up using drugs and that he would have to change his sexual behaviour; for he was aware that he could endanger others by his engaging in risky behaviour.

He had not started taking ART therapy prior to the interview but he is constantly uncertain about onset of the disease, therapy taking and expected lifetime. He has visited the HIV Clinic three times and each time he was anxious, because he was compelled to face his fears related to HIV. He got basic information about HIV at the Male Ward from his doctor about how the disease is transmitted and on how to care of his own health. He says that he has not received additional information about HIV and, in fact, does not want to know more about it.

He expects a court trial soon, so it is possible for him be released from prison in two months. He has been under pressure lately, in terms of thinking about his situation and life plans. There are many unsolved issues he has to face: how to go for treatment, settling the matter of medical insurance, where to live and find employment, how to fit into an environment which is not familiar to him, and the fear of rejection from people because he is a foreigner, ex-convict and drug-addict. Whenever faced with these issues, he becomes overwhelmed, anxious, and feels like a «time bomb». In prison he feels somewhat safe because he is accepted by the environment, other prisoners know about his status and accept him: *«Other prisoners help me very much, they encourage me and help when I am sad, each joke helps me not to think about myself and what will happen when I go out»*.

He has never asked for professional psychological assistance because he thinks that nobody could understand his situation, and because he believes psychologists and psychiatrist at Male Ward are much too busy with other jobs.

After being released from prison, he expects to live with his mother and brother who were currently in prison as well, but he has no firm plans. He has not seen his family for all the time of his being in prison. He talked to his mother on the telephone and told her that he was HIV positive. His mother is supportive.

## 5. Conclusion and Recommendations

### 5.1 Conclusions

Research shows that numerous stressors have a negative impact on the quality of life and mental health of PLHIV, as well as their ability to cope with the problems. The most frequent problems with mental health for PLHIV are grief and depressive feelings, followed by anxiety, restlessness and side effects from the use of ART. Vulnerability to stress is intensified after learning about HIV positive status, while at the same time resources for managing stressful situations become limited.

Doctors who treat PLHIV emphasize that transitional changes of the mood are frequent with this population due to life stressors effecting their quality of life and mental health, and so they should be considered separate from clinical depression manifestations. For example, in lives of PLHIV there are frequently episodes of mourning for the loss of a friend or partner, grieving for an uncertain future, and stress associated with stigma and discrimination.<sup>38</sup>

In view of these issues, our research also shows that there are numerous external factors that influence the quality of life of PLHIV. Stigma and discrimination have a negative impact on PLHIV, which leads to social isolation and chronic suffering, possibly provoking negative feelings and low self-respect.

The most frequent factors causing stress are:

- stigma and discrimination
- disclosing HIV positive status to others,
- introduction of the therapy and hospitalization related to HIV,
- uncertainty of the therapy and treatment availability,
- unemployment,
- perception that the state and family do not take care about them,
- therapy side effects management,
- reduced access to information related to medicaments stocks.

In terms of the development of psychological disturbances, the time of HIV status discovering and the problem associated with status reporting seem to be particularly important facets. Participants in our focus groups have usually learnt about their HIV status in the symptomatic phase, a situation implying higher stress and more expressed psychological disturbances. Therefore, the characteristics of participants should be taken into account when interpreting the obtained results. An important characteristic of the participants in this research is that these are PLHIV whose experience living with HIV has lasted for some years and who have developed successful strategies for coping with these challenges. Also, participants of this focus group discussion have disclosed their positive status to other people which offered them further opportunities to obtain the necessary social support.

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<sup>38</sup> Elkin, E.(2000):Mental health, Body positive  
<http://www.thebody.com/content/art30636.html>

Our research has shown that PLHIV use mostly active management strategies, such as helping other PLHIV, participating in PLHIV associations, and socializing with other PLHIV who are full of optimism and who have developed “skills of living with HIV”. Therefore, it may be assumed that the population of PLHIV who have learned recently about their status or are not members of the existing associations may have different methods for stress and problems management in psychosocial adaptation. What has been found to differ between drug users and non-drug users is the fact that drug users use more passive strategies in stress management, reflected in the use of drugs and sedatives, as well as attempts to avoid or move away from the problem.

Social support of family and friends is an important source in overcoming and facing everyday problems. The HIV Clinic is still the only place where PLHIV feel supported and safe although many of them are aware of the limited capacities and inability of personnel at the Clinic to respond to the needs of all PLHIV. The focus is often directed to physical health alone, while the problems related to mental health are frequently not recognized either by professionals or the very PLHIV.

Lack of trust in governmental institutions and uncertainty in regards to therapy availability greatly reduce optimism and hope for many PLHIV that it is just as possible to live with HIV as with any other chronic disease. Gaining the perception that the state takes care of them as well as having a transparent system of therapy provision would be, in that sense, an important resource for problem management and a sense of safety for PLHIV. Medical workers may also contribute to a better quality of life for PLHIV through gaining further knowledge about the problems PLHIV face, including the mental-health aspects of HIV and AIDS, quality service provision, and an attitude of acceptance and non-discrimination.

## 5.2 Recommendations

### 5.2.1. Recommendations to governmental sector

- **Improve HIV treatment access, quality of service for PLHIV mental health, treatment and care**

In the first place, the very important thing is to improve PLHIV's access to treatment. As the Imperial College research has shown, the fragility of access and delivery remains an on going concern of PLHIV. This has affected PLHIV's perception of whether HIV is a manageable chronic illness. In this situation, PLHIV are mostly focused on HIV treatment without considering their mental health difficulties. This uncertainty is a great source of anxiety, depression, and hopelessness. It is important to improve capacities of the HIV Clinic as well as in other centres for PLHIV treatment that will soon be opened in Serbia, since these institutions represent places where the support system and treatment is accessed. The appearance of Ward No.6 premise, where PLHIV come for treatment, proved to be important for PLHIV wellbeing and mental health; therefore, it is necessary to put efforts to improving the aesthetic condition of that institution. It is also necessary to expand advisory services in terms of the number of psychologists and psychiatrists who will specialize in work with PLHIV, for it has been proved that the existing capacities of one psychologist working half-time does not satisfy the needs of beneficiaries.

- **Organization of the service to meet the needs of PLHIV, related to mental health**

The research has shown that there is a wide range of problems related to the mental health of PLHIV who have not undergone treatment, greatly reducing the quality of life for PLHIV. A mental health component that has not been recognized at the governmental level is the need for a framework to respond to the HIV epidemic. A lack of framework has lead to the reduction of efficiency in existing services, which deal only with physical health of patients. For that reason, there is a need for a systematic approach in the organization services for PLHIV, which would create a number of new jobs for professionals in the field of mental health who are specialized for PLHIV problems and treatment. The state needs to involve the non-governmental sector in the organization of the service, utilizing the capacity and experience of non-governmental organizations in this field.

- **Develop and implement educational programmes for medical workers and other professionals aimed at modifying stigma and negative attitudes towards beneficiaries and their families**

This research has proved the existence of stigma against PLHIV in Serbia, comparable to the findings of previous studies. Discriminative reactions, especially by medical workers, have induced a negative impact on the mental health of PLHIV, weakening their capacities to cope with problems or take a more active role in advocating for their own needs. It is therefore necessary that governmental institutions, who are very influential, take the leading role in efforts to improve the

service quality of HIV and AIDS care - by investing professional development of employees who work in the system's institutions.

- **Building referrals between the existing services and professionals who work with PLHIV**

In order to ensure that every person receives corresponding treatment based on his/her needs, it is necessary to link all organizations engaged in the area of HIV/AIDS and mental health, including governmental and non-governmental institutions, PLHIV associations and other actors who deal with improving the quality of life of PLHIV. Research shows that there are existing mental health services that are not used by PLHIV, because of their fear of discrimination and their failure to recognize their own mental health needs. This further complicates the referral procedures and perceptions that resources are limited and doctors lack time and sufficient knowledge for PLHIV treatment. It would be useful for service providers to have a structured and clearly prepared referral procedures, based on the competences, responsibilities and liabilities of fellow service providers and the rated service quality, as opposed to personal contacts with cooperative individuals.

- **Ministry of Health should take more active attitude in responding to needs of PLHIV having MH problems**

The Ministry of Health has available capacities to initiate changes, including the possibility of direct action implementation, which is one of the ways to support programmes that are oriented to PLHIV quality of life. Accreditation of trainings for agents of changes could be implemented by the Expert Centre for mental health and HIV/AIDS, and supported by all other activities in the field of PLHIV mental health improvement. Hence, there would be the involvement of a greater number of PLHIV in governmental activities in the field of HIV and AIDS fighting, as well as support from other groups for advocacy, including NGOs, PLHIV families, and others.

- **Government has to regulate implementation and protection of PLHIV human rights through legislation**

It is necessary to pass laws which will be directed at resolving problems of stigmatization of PLHIV and double stigmatization of HIV positive persons having problems with mental health. Further, it is necessary to regulate the rights of patients under treatment, define sanctions against professionals who reject treatment to PLHIV, and regulate the right to employment, pension and social benefits for PLHIV. Lastly, it is necessary to support initiatives in order to use legal opportunities aimed at alleviating financial problems faced by PLHIV because of the disease.

- **It is necessary to achieve better information dissemination since it gives the feeling of control and helps PLHIV or affected persons to interpret and understand the disease and cope with HIV infection more easily**

**PLHIV:** Information regarding health issues related to HIV is necessary, including information about health protection, treatment selection, therapy progress and signs of progress, side effects, necessity of consistently applying the treatment regime, availability of the therapy and means for status monitoring. Information about places which provide emotional support, including PLHIV associations and

other organizations that may respond to their current needs, is needed. Information about problems management and adaptation to living with HIV, rights related to their employment and pensions, social services resources, and places which provide instrumental assistance to PLHIV in terms of practical assistance in everyday needs (like transport, shopping, and chores...) would be ideal. For PLHIV who are also IDUs, it is necessary to provide information about double treatment, because doctors often do not provide information about ART and maintenance programmes, priorities in the therapy, and side effects of the therapy. Hence, many PLHIV lack basic information about the necessity of proper therapy use.

**For family members and partners:** Information would be helpful about how HIV is transmitted, risks for themselves, and what changes are to be expected regarding the HIV positive status of their family member. In addition, information about the role family members can play in helping their HIV positive family member could be beneficial for all.

**For wider public:** Clear and unambiguous information about HIV infection with the emphasis on messages that are destigmatizing and inclusive of PLHIV into society is very needed in the public arena. Preventive HIV campaigns often merely include very basic information about the transmission and the necessity of condoms use; however, a greater emphasis should be placed on HIV positive persons, their needs and the obligation of the society to accept and assist them in improving their health condition and social status.

**For professionals:** Information about mental health problems PLHIV commonly suffer from and the specific needs of PLHIV are vital for professionals to have. Also, promotion of confidentiality instead of secrecy of serostatus is a necessity.

One comprehensive way to better achieve information could be in the opening of some kind of Informative Centre for PLHIV, their families, partners and friends. However, it is important to note that information should be gained within the framework of a holistic approach, implying integration of efforts in PLHIV destigmatization and PLHIV treatment and care improvement, keeping in mind that being informed is often not enough to change attitudes.

- **Need to support existing PLHIV associations in the country**

Associations of PLHIV tend to lack resources, skills and influence on how to advocate and lobby for their needs. It is therefore necessary to put efforts in teaching these organizations about capacity building and how to be more actively involved with governmental institutions. The state needs to help PLHIV to articulate their vision of the services they would like to have. It is especially important to strengthen capacities of associations of PLHIV, who have experienced drug use, for there is a complexity of their problems which includes addiction problems, more complex therapy treatment, double stigmatization, and insufficient capacities.

## 5.2.2. Recommendations to non-governmental sector

- **Government lobbying of as well as assistance to governmental institutions in organization of the services which would meet the needs of PLHIV related to mental health**

The non-governmental sector should take advantage of its position, as well as experience in the field of HIV and lobby for the expansion of the existing and opening of new services for mental health. NGOs have available capacities to initiate projects aimed at improving PLHIV quality of life, but they need support from the state in order to ensure sustainability of these initiatives. The needs for sustainable services for PLHIV is realistic, especially considering the complex needs of beneficiaries and the trend this epidemic is taking. Services should be based on the clients needs and should involve other beneficiaries that may be affected by HIV, such as PLHIV family members, partners, friends, etc. It seems that there is a special need for establishing sustainable self-help groups, for they have proved to be significant in practice because they provide emotional and informative support. Homogenous groups seem to be more recommendable in regard to the current situation and previous experience in forming of self-assistance groups. Some other forms of support may be considered, as well, such as advisory service for PLHIV, hot-lines, peer groups, etc.

For PLHIV, it is also very important to have the support of close social environment (family and friends, colleagues etc), for this could prevent and alleviate emotional distress related to chronic diseases like HIV infection. It is therefore important to support all the people who are closely related to PLHIV, in order to provide more adequate support to PLHIV, and also to improve their quality of living. This can be achieved through program support development intended for family members, friends, colleagues and all others that may be affected by HIV.

- **NGOs should establish more useful communication with PLHIV**

PLHIV are still distrustful in terms of cooperation with the non-governmental sector, especially those with insufficient experience in living with HIV and who lack information about NGO resources available for use. One of the steps towards communication improvement could be for NGOs to approach PLHIV associations and initiate joint activities directed to the needs of PLHIV, with full consideration and compliance to PLHIV proposals. In the area of PLHIV mental health, it is important to establish cooperation not only with beneficiaries, but with their families, as well as with professionals in the area of mental health, with the purpose of articulating requests concerning HIV and mental health.

- **Education of professionals about HIV aspects related to mental health**

Non-governmental organizations should take advantage of their experience and capacity in education of professionals working with PLHIV. Besides the basic corps of knowledge about relatedness of HIV/AIDS and mental health, an important aspect in education should be promotion of confidentiality principles (contrary to secrecy), and understanding of the far-reaching implications of unnecessary status revealing, as well as treatment of double and triple stigma of PLHIV (having mental health and addiction problems).

- **An improved referral system within the HIV/AIDS field (governmental and non-governmental sector)**

Cooperation and connection between government and non –government sector is inadequate at the national level. Views and recommendations of NGOs in decision and policymaking are often neglected even though they have much more capacities and recourses than government institutions. Changing this perception of NGOs is one of the challenges.

- **Stronger cooperation with media in advocacy activities**

Media should be used as an instrument for raising awareness about mental health problems in the context of HIV. This may be achieved through education and training of journalists on mental health aspects of HIV and AIDS and on the necessity of addressing double stigma as a problem faced by some PLHIV. Media organizations should also be taught how to take a more active role, and to understand the role they play in the creation of public opinion about PLHIV.

- **Decrease isolation of PLHIV in prisons in terms of information and support**

One of the biggest problems of PLHIV in prisons is their isolation from other institutions, organisations and programs related to HIV. Even the National Strategy for HIV recognized them as a vulnerable in terms of HIV, and they are still outside of prevention programs. It is necessary to improve treatment literacy, access to information about organisations active in the field, PLHIV associations and others who provide services for PLHIV.

### 5.2.3. Recommendations for GIP

- **Support and on-going contact with change agents, not only through trainings, but through networking opportunities as well**

It seems necessary to establish a of network to connect professionals in the fields of HIV and mental health, and enable the agents of change to continuously exchange knowledge and experience in practice. It is particularly important to engage PLHIV, PLHIV family members, partners and friends, so that the agents of change network will have a clear vision and orientation to the real needs of beneficiaries.

- **Connecting of Expert centre for HIV, AIDS and mental health to mental community mental health centres**

Activities of the Expert Centre for HIV/AIDS and Mental Health could be significantly supported through cooperation with mental health centres in the community, to be opened across the country within the framework of the mental health system. Mental health system reforms should take into account specific problems of vulnerable groups such as PLHIV. Through common activities in the field of decision making and advocating of both sides, it is possible to gain a better understanding about the relationship between mental health and HIV, and in that way improve the quality of mental health services for PLHIV.

- **Double stigma treatment**

Possibilities of long-term and comprehensive influence, oriented to the reduction of stigma towards PLHIV, should be considered. In the context of double stigma treatment, it is necessary to direct efforts toward destigmatization of IDUs and homosexuals as well, and not simply toward PLHIV. It was shown that not all PLHIV were discriminated in the same way, so it is necessary to pay attention to these specificities, and in relation to these, create anti-stigma campaigns and messages as well as other activities aimed at reducing stigma in this field.

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## **Appendix 1- Questionnaires for Focus Groups**

### **Questionnaire for the focus group held with the aim of assessing PLHIV' using of mental health service**

1. How did your awareness of being HIV positive impact your living?
2. Did you feel the need for psychological assistance/support after discovering of HIV status?
3. Who helped you most?
4. Have you addressed professionals for psychological assistance?  
If the answer is Yes, whom did you address and to which extent it responded to your needs? What was good? What was missing? If the answer is No, why?
4. What should be changed in the health system, in order your needs be satisfied?

### **Questionnaire for a focus group with PLHIV aimed at assessment of mental health problems**

#### *I- Identification of PLHIV mental problems*

1. Since you have learnt about having HIV, has anything changed and what in terms of how you experience yourself?
2. What feelings/moods have been occurring since discovering of your HIV status?  
How long have such moods lasted/last?  
What kinds of thoughts accompany such feelings/moods?  
Did you have any bodily manifestations accompanying such feelings and moods?
3. How such feelings, moods effected or effect relations with others?
4. How they effected or effect fulfilments of everyday obligations? (*Going to work, school obligations, care about own health, visiting doctor, housework, everything that was occupying their time*)
5. In such moods, have you had or do you have a need for alcohol, drugs, medicament (*how do you usually overcome (manage) stressful situations*)?
6. How such moods have effected or effect your sexual behaviour? (*use of preservatives, change of a number of partners, HIV status of a partner, revealing own HIV status to a partner*)?

7. How such moods have effected or effect ART taking?

8. Do you see any relatedness between ART and mood?

9. Had such feelings occurred earlier, before you learnt of having HIV? What were your thoughts like and what did you do when such feelings occurred? Have you taken or take medicament that helps you feel better? Have doctors prescribed them or you have been taking them in your own way?

*II – Identification of factors which effect PLHIV mood*

10. What affects such moods occurrence, what effects their intensity and duration?

11. What was disturbing you and what is disturbing you now so you cannot feel good?

12. What do you think may possibly disturb you in future to prevent you feel good?

13. What helped you most to feel better since you had become aware of living with HIV and how? How would you help someone in the similar situation to feel better?

**Questionnaire with socio – demographic data**

1. Sex M F

2. How long have you been living with HIV?  
\_\_\_\_\_

3. Are you taking ART therapy? YES NO

4. Years of age \_\_\_\_\_

5. Place of birth  
a. village  
b. small town  
c. big town

6. Education  
a. low  
b. secondary school

c. college/university degree

7. Marital status

- a. single
- b. in relationship
- c. married
- d. widow/widower
- e. divorced

8. Employment

- a. permanent employment
- b. part-time employment
- c. illegal work
- d. unemployment
- e. pensioner

Questionnaire for PLHIV, intravenous drug users, apart from questions mentioned contains the following block of questions:

9. How long do you use or were using drugs?

10. How many times a week do you use drugs?

12. Frequency and drug dose taken depends on:

13. Which kind of drug do you use? (or you take substitution therapy?)

## **Appendix 2- Questionnaire for the professionals working with PLHIV**

- a) According to your opinion, what are the most frequent problems related to PLHIV mental health?
- b) In which situations people address you most frequently?
- c) How do you make difference between transient, adaptive reactions of adaptation to stress and introduction into psychiatric disturbance?
- d) According to you, what effects occurrence of mental disturbances in PLHIV? Are there any specific circumstances in which they occur?
- c) What strategies do PLHIV use in overcoming difficulties?
- d) What differs PLHIV coping with the infection well, from those having mental health problems?
- d) Which factors effect the living quality of a PLHIV or AIDS? (therapy, relations with others, support...)
- f) How PLHIV may be assisted in overcoming mental health problems?