Phase 1 of the Research

MAIDS: Report on the 1st Phase of the Research project

NEEDS IDENTIFICATION IN THE AREA OF MENTAL HEALTH AND HIV

MAIDS Mental Health and HIV/AIDS

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IN THE AREA OF MENTAL HEALTH AND HIV

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1. INTRODUCTION

Mental health is intrinsically related to HIV/AIDS, both as a cause and as a consequence. The serious nature of AIDS, its social perception as a plague of the XXI century, and the high level of discrimination and social exclusion related to it are very likely to lead to psychological stress and serious mental disorders for those infected and for those close to them (relatives, partners). Moreover, persons with mental illnesses or a mental handicap run a higher risk of becoming infected with HIV. In spite of these realities, the relationship between HIV/AIDS and mental health is often neglected or ignored. Contemporary medicine is preoccupied with inventing new pharmacological recipes to save lives, and improving quality of life seems to be forgotten or considered to be of secondary importance.

People living with HIV/AIDS experience many psychological and social problems in their every-day life. They meet with discrimination and rejection and experience fear and lack of social acceptance. Providing them with appropriate psychological and psychiatric care, as well as with social support and counselling, can contribute to improvement of their quality of life. It may also prevent further infections. Psychological support helps infected persons accept their diagnosis and learn to live with it. It allows them to deal with everyday problems related to HIV, not only those of a psychological nature. This involves a change in life-style and taking more responsibility for their own health and the health of others.

The important issues in health care for people living with HIV/AIDS are problems of psychiatric co-morbidity and provision of adequate mental health care. Dual and triple diagnoses are established when next to the HIV infection a mental disorder or a mental disorder together with dependence on psychoactive substances is diagnosed. Providing psychological and psychiatric care for people living with HIV/AIDS who also suffer from mental disorders is crucial for the effectiveness of antiretroviral therapy. A person's physical and psychological state can significantly influence continuation and compliance in antiretroviral therapy. Alcohol and other psychoactive substances can cause a weakening of the organism and the medicines taken can interact with each other. It is therefore important that care for people living with HIV/AIDS who suffer from mental disorders has an integrated character.

For this reason, a study investigating the relation between mental health and HIV/AIDS as well as the problems related to accessibility and adequacy of mental health care and psychological and social support for people living with HIV/AIDS will have important theoretical and practical significance.

The main purpose of this project is to contribute to improving the quality of life of people with double/triple diagnoses (HIV, addiction, mental illness) in new EU countries, by bringing forward more evidence related to the issue. In doing this, awareness of the relationship between HIV/AIDS and mental health problems among professionals may be increased. The aims of the study are to identify the special needs of People living with HIV/AIDS (PLHIV), to define the barriers to satisfying these needs, and to outline possible solutions. Thus, the project went beyond the simple needs assessment foreseen in the initial project proposal.

The new EU countries have a different (usually shorter) history of HIV, different traditions of general and mental health provision, and less resources to invest. For these reasons research was identified as a priority in the project. The aim was to gather empirical evidence about the link between HIV/AIDS and mental health in nine countries of Central and Eastern Europe, located between the Baltic, Adriatic and Black Seas, i.e. from Estonia in the North-East, to Slovenia in the West and Romania in the South.

2. PARTICIPATING COUNTRIES

The nine countries that participated in the research part of the project are:

- Czech Republic,
- Estonia,
- Hungary,
- Latvia,
- Lithuania,
- Poland,
- Romania,
- Slovakia,
- Slovenia.

These nine countries have several things in common. They share a common political history (including domination of mono-party political systems and centralized economies in four post-war decades, as well as rapid transformation towards political pluralism and a market economy in the 1990s) and a late outbreak of HIV epidemics. Nevertheless, they are not very homogeneous at all. Among them are for example on the one hand the three Baltic republics (Estonia, Latvia, Lithuania) which belonged to the Soviet Union for about fifty years, and on the other hand Slovenia, which used to be a Yugoslav republic and as such never belonged to the Warsaw Pact and enjoyed more political freedom than any other country of the region.

There are huge differences in levels of prosperity, ranging from Slovenia with a GDP per capita approaching the EU average, to Romania where the GDP is half of that of Slovenia.

Life expectancy also varies widely, with a ten year gap in male life expectancy between Slovenia (76 years) on the one side and Latvia and Lithuania (66-67 years) on the other. Health inequalities are also reflected in excess male mortality which is about 12 years in the Baltic countries, meaning that women live 11-12 years longer than men. Last but not least, there are significant differences in population numbers, from Poland with its 38 million inhabitants to Estonia and Slovenia with less than 2 million inhabitants each.

Table 1. Basic characteristics of participating countries (2008)

Country	Size sq. km x 1000	Population in millions	Real GDP (PPP) per capita, USD	Life expectancy at birth	
				Male	Female
Czech Republic	78.9	10.5	24 769	74	81
Estonia	45.2	1.3	20 699	69	80
Hungary	93.0	10.0	19 277	70	78
Latvia	64.6	2.3	17 148	67	78
Lithuania	65.2	3.3	18 942	66	78
Poland	312.7	38.1	17 675	71	80
Romania	238.4	21.5	14 297	70	76
Slovakia	49.0	5.4	22 041	NA	NA
Slovenia	20.3	2.0	27 814	76	83

3. METHODS

Multiple research methods were applied to investigate the link between HIV/AIDS and mental health in the participating countries. Due to extremely limited funding, the project had to be restricted to qualitative approaches, as any random survey to assess the prevalence of mental health problems among PLHIV and their needs was well beyond its scope. This report will offer an overview of the three studies completed within the project:

a) epidemiological assessment,
b) Delphi study,
c) focus group study.

A) EPIDEMIOLOGICAL ASSESSMENT

Instead of implementing a huge survey, the project elaborated a relatively simple methodology to estimate the proportion of persons with mental disorders among PLHIV registered in existing public health structures that address specific needs of PLHIV.

A random sample of patient files on people treated for HIV/AIDS was selected from one or more specialized centers. Then a set of basic data - introduced in a special form – was extracted, including gender, age, year of HIV infection testing and mental health status.

B) DELPHI SURVEY

Expert perspective

The objective of the Delphi survey was to collect expert opinions on needs, barriers and relevant solutions in the area of mental health care for people living with HIV/AIDS, while taking into consideration major transmission routes in participating countries. A crucial element was to reach a consensus on these issues among the group of experts in a country.

The Delphi method is a problem-solving method used to identify and reconcile the knowledge, judgements and opinions of several experts. Consensus is reached through several cycles of revision, based on feedback surveys by specifically selected experts. Experts work on their answers individually and give their opinion/feedback anonymously.

In the context of the Delphi process, experts on somatic and mental health care for people living with HIV/AIDS expressed and exchanged their opinions on the research questions. Consecutive rounds of the Delphi process are based on the experts' e-mail feedback in response to special forms prepared by a research team for every round of the process. In Round 1, experts express their opinions by answering open questions, including questions on the needs of PLHIV, barriers to access to appropriate care and recommendations on possible solutions. The form for Round 2 is prepared by a research team on the basis of the input in Round 1. All expert answers are grouped into wider categories (summary categories) and then listed in the form for Round 2. On these forms, experts rate which answers are particularly important in terms of the study questions (using a simple scale, e.g. from 1 - not important, to 5 -very important). A consensus on which summary categories are of importance is to be reached in Round 3. On the forms for Round 3 – which are prepared individually for each expert - his/her original ratings for each summary category are compared with average ratings of all experts. In that way every expert has a chance to think over their rates for each question, taking into consideration other experts' opinions. Eventually, an order of summary categories which have similar ratings emerges, and may serve to establish priorities regarding particular issues investigated in the Delphi process.

The most important criteria for selection of experts in this study were their expertise in the area of health care and mental health care for people living with HIV/AIDS and their expertise in working with the main transmission groups. Experts were to have knowledge of the subject and represent different fields of professional experience. In each participating country the final expert list was to consist of about 12 persons (this number differed depending on country-specific considerations), with among them representatives from:

- health care
- mental health care and addiction therapy centres
- NGOs
- academic centres
- public institutions (local and national administrations, public administration agencies)

C) FOCUS GROUPS - staff and client perspective

The focus group approach was applied to identify needs, barriers and good practices in mental health care for people living with HIV/AIDS. Focus group discussions belong to the category of qualitative research approaches. They do not assess prevalence of phenomena, opinions or attitudes, but present variations and study mechanisms of their action. Focus group were to consist of 6 to 10 persons, who in the course of a discussion attempt to find responses to several research questions. The focus group discussion were to be no longer than two hours and to be moderated by an experienced person. This moderator ensures that all research questions are discussed and that all participants contribute without domination of the discussions by one or two influential individuals. In addition, the moderator prevents that two or more participants speak simultaneously and creates a friendly and civilized atmosphere. Most importantly, the moderator facilitates proper recording.

Discussion should be recorded (tape recorder, camera) and it is recommended that written notes are taken by another person assisting the moderator. Recording should not take place without the consent of all participants. If they do not agree, the written notes have to be very detailed, including precise quotations.

In each country, a number of focus group discussions were carried out with medical staff and persons with HIV/AIDS. In order to secure a level of homogeneity, several focus groups were considered in each research site, including at least one made up of medical staff and one made up of people living with HIV/AIDS. Topics covered needs, barriers and good practices, including (non-existent) practices recommended by participants. Gathering the opinions of different professional groups and clients provided an opportunity for more thorough assessment of needs, and identification of ways in which those needs can be met. Identifying potential discrepancies in the perspective of service providers and clients may have crucial significance for social dialogue and improvement of the existing care system.

4. RESULTS

A) EPIDEMIOLOGICAL ASSESSMENT

The epidemiology of HIV/AIDS differs from country to country in terms of major routes of administration as well as prevalence and incidence rates.

Table 2. Registered prevalence of HIV and AIDS by country

Country	Major route of administration	Cumulative number of infections		Number of AIDS cases		Last year's HIV incidence per million
		Number	Per million	Number	Per million	
Czech Republic	MSM	1 522	148	321	31	18
Estonia	IVDU	7 320	5 631	290	223	307
Hungary	MSM	1 911	191	617	62	
Latvia	IVDU	4 614	2 006	820	357	158
Lithuania	IVDU	1 581	479			
Poland	IVDU	12 689	333	2 305	61	18
Romania	MSM	16 697	777			22
Slovakia	MSM	318	59	55	10	8
Slovenia	MSM	449	225			24

* MSM = Men who have sex with men – IVDU = Intravenous Drug Use

These data show that both prevalence and incidence of HIV/AIDS differ enormously. The highest rates are recorded in Baltic countries, first of all in Estonia where the cumulative HIV rate approaches six thousand per million inhabitants, followed by Latvia with two thousand infected persons for one million residents. On the opposite side there is Slovakia, where the rates are almost 100 times lower. Medium rates between 150 and 300 per million are recorded in all remaining countries, with the exception of Romania, where the rate surpasses 700 per million and where one third of all infections represents persons infected in the late 1980's due to blood transfusion with either infected blood or non-sterile injection equipment.

Data from Estonia show a number of AIDS cases that is disproportionally low compared to the number of infections (ratio of 1:25 compared to 1:5 in the other countries). This may be due to inaccurate data, diagnostic practices and/or limited access to diagnostic services compared to testing ones.

Differences in recent incidence rates are smaller, suggesting declining trends in high prevalence countries. Nevertheless, in Estonia and Latvia incidence rates are several times higher than the EU average, while in the remaining countries they are several times lower.

Routes of transmission also differ in participating countries. In four of them - Estonia, Latvia, Lithuania and Poland – the majority of infected inhabitants are injecting drug users. This can be related to their geographical vicinity, but also to a similar drug use pattern of injecting domestic opioids. Despite similar patterns, it has to be stressed that Polish prevalence rates are about ten times lower than in Estonia and Latvia. In the remaining countries more than half of all PLHIV got infected through male heterosexual relationships. The differences in routes of transmission largely reflect the beginning of the HIV epidemics in the participating countries. Currently, variation tends to disappear, with heterosexual infections growing faster than other routes of HIV transmissions.

An attempt to estimate prevalence of mental disorders among PLHIV failed in all countries but Poland and the Czech Republic. Despite the fact that all data were supposed to be collected anonymously, the major cause of failure were legal provisions protecting individual data in the individual countries.

In the Czech Republic data were collected from a research data base with information on PLHIV participating in another study, focusing on persons who ask for psychological or psychiatric health care. In Poland data came from an out-patient clinic for HIV-infected patients. The majority of participants in both countries received anti-retroviral therapy. The size of the Czech sample was 172, while the Polish sample was made up of 200 persons. More detailed comparisons of these results are presented in table 3 below.

Table 3. Prevalence of mental disorders among PLHIV in treatment

Results	**The Czech Republic**	**Poland**
Size of the sample	172	200
Proportion of men (%)	84	77
Average age	43	39
Average number of years since	12	8

HIV detection		
Proportion with mental health disorders (%)	69	45
Type of mental health disorders (% of diagnoses):		
organic (F00-F09)	3	11
psychoactive substance use including alcohol (F10-F19)	21	57
schizophrenic (F20-F29)	2	5
affective (F30-F39)	18	14
Neurotic (F40-F49)	5	10
personality (F60-F69)	43	2
other	4	1

Despite different ways of data gathering, the samples are more similar than different. In both samples men dominate, representing around 80% of the subjects. The average age was around 40 years in both cases, while the average time since HIV detection was around ten years. In general, the Czech sample was a bit older, and therefore tended to have lived with HIV/AIDS for longer. In both samples there was a significant proportion of people with mental disorders, with the figure reaching almost 50% in Poland and over two thirds in the Czech Republic. The distribution of diagnoses, however, was different. First of all, more than half of the mental disorders in Poland was due to psychoactive substance use, of which the majority were illicit substances. In the Czech this figure was 21%, of which half could be attributed to alcohol use. This discrepancy reflects well the pattern of the epidemic in Poland, where - unlike in the Czech Republic - HIV appeared first among intravenous drug consumers. They still make up more than half of PLHIV in Poland. The high proportion of persons with personality disorders in the Czech sample represents another striking difference, which could be due to the specificity of mental health problems in both countries, to different diagnostic practices, or to sampling bias.

In addition to these systematic attempts made in the Czech Republic and Poland, the Romanian report presents data about the mental health status of 94 PLHIV, collected by the Romanian association against AIDS. No information was offered on how the data were collected, how the mental health status was established or to what extent this sample may be representative of PLHIV in Romania. Nevertheless, the data show that 25% of all subjects had a mental health diagnosis and that depression was a prevailing diagnosis affecting 40% of those with mental health problems.

B) DELPHI SURVEY

All countries participating in the study completed the Delphi survey on needs, barriers and relevant solutions in mental health care for people living with HIV/AIDS. In nine countries, over 150 experts were approached, representing different working areas and various professional background. In total, 88 of them agreed to participate and completed the first round of the process. 70 of them finished the last round of the process. Table 4 presents the participating countries and numbers of experts.

Table 4. Countries and number of experts participating in the Delphi survey

COUNTRY	Number of experts approached	Number of experts participating	Number of experts who completed all 3 rounds
Czech Republic	12	5	5
Estonia	21	11	11
Hungary	8	4	0
Latvia	12	12	12
Lithuania	13	12	12
Poland	19	11	8
Romania	17 experts approached personally, open invitation other experts on website	11 who were approached personally, 9 from the open invitation	12
Slovakia	29	6	3
Slovenia	13	7	7

The number of experts who participated in the Delphi survey varied across the countries, not necessarily in relation to the size of their populations. Romania, the Baltic countries and Poland succeeded in involving around a dozen or more experts, while the remaining countries such as Hungary, the Czech Republic, Slovakia and Slovenia had 4 to 7 experts represented.

Table 5. shows the professional background of experts who participated in the study.

Table 5. Background of experts participating in the Delphi process in each country

COUNTRY	Health care	Mental care	NGO	Research centres
Czech Republic	Physician - infectious diseases specialist, social worker	Psychologist, HIVcounsellor, psychiatrist-sexologist	Psychiatrist-sexologist, HIV/AIDS counsellor	Psychologist, HIV counsellor
Estonia	Medical doctors, infectious diseases specialist, public health specialist	Psychologist, HIV counsellor,	NGO activist, harm reduction/ HIV prevention specialist	HIV/AIDS specialist
Hungary			NGO activists	
Latvia	HIV/AIDS treatment/prevention experts	Mental health and drug abuse treatment experts		Mental health and drug abuse treatment experts
Lithuania	Medical doctor, nurse	Psychiatrist, psychologist, social worker		Biologist, psychiatrist
Poland	Internal and infectious diseases specialist, expert on HIV infection	Psychiatrist, psychologist, methadone programme expert, HIV counsellor, addiction specialist,	Harm reduction expert, social worker, psychologist, addiction therapy instructor, pedagogue, HIV counsellor	Psychiatrist
Romania	HIV counsellor	Psychologist, psychotherapist, addiction therapist, psychiatrist	NGO activist	
Slovakia	Medical doctor, epidemiologist, nurse,	Psychologist	Social worker, NGO activist, harm reduction expert, client representative (PLHA)	Epidemiologist,
Slovenia	Infectious diseases specialist, expert on HIV infection	Psychiatrist, addiction therapy specialist, HIV counsellor	HIV counsellor, NGO activist, psychologist, sociologist,	Sociologist, HIV researcher

Experts involved in the Delphi process represented a great variation of professions: physicians of different specialisation, such as nurses, psychologists, sociologists, social workers and epidemiologists. In the majority of countries they came from different institutions such as health care services -including mental health care- NGOs and research institutions. Exceptions are Hungary, where only NGO activists participated in the survey, and Latvia and Lithuania which did not involve NGO representatives.

In the Delphi survey process the experts answered the following questions:

- What are the needs of people living with HIV/AIDS in the area of mental health care?
- What barriers obstruct access of people living with HIV/AIDS to mental health care and support?
- What should be done to provide appropriate mental health care and support for people living with HIV/AIDS?

At the stage of data processing, researchers from each country summarized the answers provided by experts into a smaller number of categories. Categories describing the same phenomenon were merged, whereas categories related to more than one phenomenon were split. In consequent rounds of the process, experts rated the importance of the specified categories and looked for consensus in their ratings. After completing the final round of the process, the final list was presented by each country, including only categories with the highest rating of importance for the given category. On a few issues, reaching consensus appeared to be a difficult task. In most countries even in the final list there were a few categories with differences in rating between experts exceeding 3 points. Table 6 shows the number of categories presented in the final national lists and the number of categories on these lists for which consensus was not reached. In two countries only, Latvia and Lithuania, consensus was reached on all three questions. However, it has to be stressed that in most countries experts managed to agree for most categories and only a few categories remained controversial. The country with the highest level of discordance was Romania, especially in relation to barriers, where out of 7 categories, consensus was not reached on 5 of them.

Table 6. Number of categories with the highest rating after the final Delphi process round and number of categories from the final list where consensus was not achieved

COUNTRIES	First question (NEEDS)		Second question (BARRIERS)		Third question (SOLUTIONS)	
	Number of categories:		Number of categories:		Number of categories:	
	with the highest rating after the final round	in the final list where **consensus was not achieved**	with the highest rating after the final round	in the final list where **consensus was not achieved**	with the highest rating after the final round	in the final list where **consensus was not achieved**
Czech Republic	10	1	10	1	10	1
Estonia	11	2	11	0	12	1

Hungary	9	-	7	-	10	-
Latvia	7	0	9	0	5	0
Lithuania	12	0	11	0	11	0
Poland	12	1	10	3	10	1
Romania	7	3	7	5	10	2
Slovakia	11	1	11	1	12	1
Slovenia	5	1	5	0	5	0

The categories from the consensus lists of each country were grouped into more general themes, in order to present the problems mentioned by experts in all participating countries. Tables 7 to 9 present grouped themes and countries which mentioned them in their final lists. There are 10 themes for questions on needs of people living with HIV/AIDS, 12 for questions on barriers to mental health care and support, and also 12 themes for questions on good solutions. Some themes are mentioned by all or most countries, while others are specific for a few or only one country. It can be concluded that some problems are common for all countries in the region and some issues are related to factors that are specific to certain countries, such as the epidemic situation, treatment and the legal system. While reading the tables summarising the results of the Delphi survey it has to be remembered that the themes or issues that emerged are ordered according to the level of consensus reached, and do not offer any coherent typology of needs, barriers and solutions.

Needs

Table 7. Needs

Themes	Summary of categories included	No. of countries mentioning theme in top 10 categories	Countries mentioning theme in top 10 categories
Access to specialised treatment and diagnostic services	Access to specialised diagnostic measures and professional care in HIV/AIDS, neurological, mental health, addiction and somatic health area, continuous specialised care and after-care for PLHA	9	ALL
Initial psychological help and support for newly diagnosed	Professional pre- and post-testing counselling, help and support to start treatment, psychological care for newly	7	CZ, ES, HU, LT, PL, SK, SL

people	diagnosed people		
Social assistance	Social security, special social assistance, possible social problems of PLHA, involvement of social workers during and after treatment, social and vocational integration, legal assistance, improving quality of live	7	CZ, LV, LT, PL, RO, SK, SL
Access to information, knowledge and education	Access to information, knowledge and education for PLHA, their families, partners and friends, for specialists and for all of society, information on treatment possibilities, side effects and prognosis, guidelines for specialists on specific needs of PLHA	7	CZ, HU, LV, LT, RO, SK, SL
Integrated character of care	Inclusion into HIV/AIDS treatment of other care (somatic health, mental health, addiction), provision of social specialists aware of the complex character of PLHA problems, dual and triple diagnosis patients, co-operation between professionals of different specialisations, case management	6	ES, HU, LV, LT, RO, PL
Psychological needs of people living with HIV/AIDS	Need for love, intimacy, dignity, partnership, friendship, family relationship, sexual needs, need to feel useful, self realisation	6	CZ, ES, PL, RO, SK, SL
Anonymity and confidentiality of treatment	Right to anonymity, privacy, treatment confidentiality, confidentiality of treatment records and personal data, confidentiality laws	5	CZ, ES, PL, SK, SL
Self-support groups	Self-support groups for different PLHA groups, peer support, support groups for family and partners, role of NGOs in organising and running different type of support and assistance	5	ES, LT, RO, SK, SL
Free of charge treatment, equal access without discrimination	Free specialised and non-specialised treatment for anyone in need, no discrimination in access,	4	ES, PL, RO, SK
Voluntary treatment and respect of patients' rights	Patients' rights to free choice of type of treatment, non-compulsory mental health treatment	1	RO

There is an overall consensus among experts from participating countries that access to specialised diagnosis and treatment constitutes the most important need to be satisfied. This includes not only HIV/AIDS-specific treatment but also somatic, neurological and addiction care. The next issue is the need for initial psychological help and support immediately after positive results of the test are communicated to the patient. Thirdly, medical treatment should be accompanied by social assistance, with a special emphasis on social reintegration. The fourth need in order of priority is to be knowledgeable about the disease. This is relevant not only for PLHIV, but also for their families and partners. Holistic and/or integrated treatment appears to be among the top priorities too, in 6 out of the 9 participating countries.

Experts from almost all participating countries consider the need for psychological support to be a priority at the initial phase of becoming aware of your sero-positive status. Psychological needs in the further course of the disease are seen as a priority in six of the nine countries. These include basic needs such as love, intimacy, sexual needs, dignity and self-realisation, followed by the basic human rights privacy, confidentiality and anonymity.

In countries where access to treatment depends on health insurance and where special procedures apply for admissions without insurance, a need for unrestricted access to treatment for PLHIV was noted, including somatic and mental health treatment.

Barriers

The experts from all countries were very much aware of existing barriers to care including mental health care (Table 8). There was a significant level of consensus that, in addition to material and organisational problems (limited number of specialists, lack of specialised services outside large cities, lack of treatment alternatives, poor co-operation among different services and insufficient training and resources), the most important barriers are social, cultural and psychological problems. PLHIV are reluctant to approach relevant services because of negative attitudes among the general public as well as medical staff. Previous bad experiences, unsuccessful attempts to get proper treatment and discrimination all contribute to building an internal barrier, to psychological resistance to admit one's HIV positive status and seek help. Negative experiences produce negative expectations, lack of trust in medical personnel, and fear of confidentiality violation.

Table 8. Barriers

Themes	Summary of categories included	Countries mentioning theme	Countries mentioning theme in top 10 categories
Stigmatisation and discrimination	Negative attitudes towards PLHA with psychological problems and gay groups, negative stereotypes, negative attitudes of health care staff towards patients with HIV	8	CZ, HU, LV, LT, PL, RO, SK, SL
Internal psychological barriers of PLHA to undergo treatment	Denial of the infection, fear and shame of treatment, fear of discrimination, previous negative experience, mental health disorders and/or addiction	8	CZ, ES, LV, LT, PL, RO, SK, SL
Limited access to mental health care	No mental health in HIV/AIDS centres, limited number of specialists and services, long waiting lists	8	CZ, ES, HU, LV, LT, PL, RO, SK
Lack of trust in personnel and in confidentiality of treatment	Fear of non-respect of confidentiality, bad practices in some services, disclosing diagnosis in medical reports/referrals	7	CZ, ES, LV, LT, RO, SK, SL
System and infrastructure barriers	Unintegrated care, lack of cooperation between services, bureaucracy, insufficient options for people with double diagnosis, lack of epidemiological data	6	ES, LV, LT, PL, RO, SK
Social problems	Social exclusion and deprivation, no health insurance, social conditions affecting mental health problems	5	ES, HU, LT, PL, SK
Lack of knowledge and appropriate training among professionals	Lack of knowledge of mental health and drug therapy specialists on HIV/AIDS issues, lack of knowledge of medical doctors on mental health and addiction issues and on social problems related to HIV/AIDS	5	CZ, LV, LT, RO, SK
Lack of knowledge of treatment options	Information on treatment options is not easily accessible, services do not inform patients and their families	5	CZ, ES, LT, RO, SK
Financial constrains in developing adequate care	Not enough funds for appropriate health and mental health care for PLHA, unstable financing of health services and NGOs, inadequate financing for addiction	4	ES, LV,LT, RO

	treatment and specialist health care in prisons		
Accessibility of care for people living outside big cities	Limited access to specialised treatment (HIV, mental health, addiction and other) and different forms of support	4	HU, PL, RO, SK
Narcological record	People who seek addiction treatment are put on a narcological record for 5 years. Therefore, they can not obtain a driver's license or get a job in certain professions	1	LT
Over-protective family	In relation to children and young people infected through nosocomial transmission, overprotective families are a barriers for social integration and treatment	1	RO

Solutions

Table 9. Solutions

Themes	**Summary of categories included**	**Countries mentioning theme**	**Countries mentioning theme in top 10 categories**
Access to specialised treatment and interdisciplinary care	Access to HIV/AIDS treatment, mental health treatment, specialised diagnostics including psycho-neurological diagnoses, and multi-disciplinary teams	9	ALL
Training programmes and supervision for specialists	Improvemed university education for specialists on issues related to HIV/AIDS and mental health, further training system for HIV/ AIDS specialists, medical staff, mental health staff, social workers	9	ALL
Prevention, education and harm reduction programmes	Prevention programmes aimed at different groups and at the general public, information on treatment options, de-stigmatisation of HIV/AIDS and different groups of PLHA, harm reduction measures	9	ALL
Promoting self-help groups and social support	Different types of self-support and peer support groups, support for family and partners, encouraging establishment of support groups, supporting NGOs in	8	CZ, ES, HU, LT, PL, RO, SK, SL

	providing support programmes		
Developing and improving the system of HIV/AIDS care	System changes, adequate funding for various treatment programmes, decentralisation, development of regional centres, supporting NGOs services, broader therapeutic offer in HIV/AIDS centres	7	CZ, HU, LV, LT, RO, SK, SL
Promoting co-operation between services	Promoting and supporting cooperation between different types of services	4	CZ, ES, HU, SL
Easier access and more professional testing centres	Guidelines for testing and counselling centres, referrals to psychological help for the newly diagnosed, procedures of referral to specialised treatment	4	ES, HU, LT, SK
Social assistance	Social workers in treatment and after-care treatment programmes, taking into account the socio-economic situation of PLHA, free mental health care for PLHA	4	CZ, LT, RO, SK
Addiction treatment	Special need for addiction treatment including methadone programmes, offer for dual diagnosis patients,	3	ES, LV, LT
Confidentiality procedures	Procedures and guidelines for data protection, anonymity and confidentiality of treatment data	2	LT, SK
Promotion of mental health	Special programmes to overcome negative stereotypes towards mental health disorders and services	1	RO
Narcological records	Cancellation of this record system	1	LT

Solutions proposed by experts from participating countries first of all include improvement of access to both specialised and mental health services, which should be offered by multidisciplinary teams rather than through elaborate referral systems. Improvement of access requires extension of university education on HIV/AIDS issues and development of training schemes for post-graduate education. The whole system of HIV/AIDS treatment and care requires significant changes: adequate funding, decentralisation, broader therapeutic offer, more co-operation within the system, and inclusion of NGOs.

On the other hand, stigmatisation - an important barrier in access - can be overcome by public education and prevention programs targeting the whole population and more specific target groups.

A crucial role can be played by voluntary associations and self-help groups, supported by the governmental sector.

There are solutions/recommendations which are relevant in a few countries only. Two of these are cancellation of the special registration system for drug addicts, which excludes a person registered from certain occupations, and provision of addiction treatment within HIV/AIDS care, recommended by all Baltic countries, because intravenous drug use is still a major route of HIV infection there.

C) FOCUS GROUPS - staff and client perspective

Needs, barriers and priorities - staff perspective

In spite of a different methodology, focus group discussions with professionals revealed problems and priorities similar to those of the Delphi survey. An advantage of the Delphi process is that in addition to specifying important issues, it reports on the level of consensus, and orders the priorities accordingly. The focus group approach on the other hand, facilitates typification of issues and helps identify theoretical dimensions of the analyses.

Arranging for focus group discussions with participation of professionals was not an easy task. This was due to their tight time schedule on the one hand, and general reluctance to participate in social research in their field on the other. Three countries failed to organize focus groups and the total number of group discussions that took place was not high. Out of ten focus groups three were conducted in Estonia, two in Lithuania and Poland, and one in Hungary, Slovakia and Slovenia[1].

Table 10. Number of focus groups and their participants

Country	No.	Type of group	No of participants	% of men
Czech Republic	0			
Estonia	3	Health service NGO Health service	3 4 5	66 100 20
Hungary	1	Health professional, two NGO members, two researchers	5	n/a
Latvia	0			
Lithuania	2	Health service (nurses) Health service (doctors)	11 12	0 0
Poland	2	Health service (mixed)	4	0

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[1] In the Czech Republic, where attempts to bring together focus groups failed, 73 professionals were approached by e-mail to respond several open-ended questions on experiences with discrimination and stigmatisation, gaps in mental health care provision and situations threatening mental health for PLHIV. The response rate was approximately 18%. The results of this survey are available in the Czech national report.

		Health service (doctors)	3	66
Romania	0			
Slovakia	1	Mixed	4	25
Slovenia	1	Health service (two doctors and three nurses)	5	n/a

The participants were asked to discuss three major issues:

a) problems of PLHIV and barriers in access to care
b) needs of PLHIV
c) ways of overcoming barriers

Pilot focus groups were convened in Poland and the discussions were transcribed and then analysed. Two persons did the coding work independently of each other, then agreed upon common coding categories. Coding categories identified in the Polish study were then suggested as an analytical framework for other participating countries and proved their usefulness in other settings. As a result of the extensive coding of the Polish material, all issues identified were located within a multi-dimensional space organised along two axes:

- structural (societal, institutional - health care and individual)
- attitudinal (knowledge, attitudes, behaviours)

a) Problems and barriers

Problems and barriers at societal level

In spite of a decade-long history of HIV epidemics in most countries, the level of knowledge about HIV/AIDS in society (in particular as regards routes of transmission) is still unsatisfactory. This is very likely to produce negative societal attitudes, varying from isolation to physical aggression, including discrimination on the labour market.

In addition to HIV-specific prejudices, PLHIV are exposed to double or triple stigma, stemming from a negative perception of homosexuals or drug addicts, refugees and homeless people, traditionally suffering from discrimination and poor access to health and social services. Stigmatisation of mental health problems increases the level of stigma of PLHIV and reduces their willingness to seek psychiatric help.

Problems and barriers at health care level

Poor knowledge and often ignorance on HIV/AIDS prevail among people in the medical professions too. Negative attitudes and stigmatisation resurface repeatedly in direct contact between "an average physician" and PLHIV. Lack of competence and skills in this area may lead to indifference or even refusal to offer any treatment.

Limited access to general health services can hardly be compensated for by specialised services for people with HIV/AIDS. The network for this is poor and limited to large cities, and collaboration between specialised services is insufficient or non-existent.

As in most branches of medicine, a holistic approach may only be dreamt of. Psychiatric or psychological help is of secondary importance, a phenomenon reflected by the low number of psychologists/psychiatrists qualified to help PLHIV, and reinforced by insufficient or poor quality of mental health care.

Problems and barriers at individual level

PLHIV suffer from a variety of mental disorders: depression, substance abuse, organic disorders, neuro-cognitive disorders, and from anxiety and cognitive impairment associated with their disease, behavioural problems, and denial of the problems.

These mental health problems are associated with and reinforced by deterioration of psychological well-being in their natural environment. People are ashamed to admit their HIV status, in particular in smaller towns, which leads to self-marginalisation. The shame of being seropositive is multiplied by the fear/shame of being labelled as a psychiatric patient, which reduces the likelihood of seeking mental health care in all but severe cases.

b) Needs of PLHIV

According to staff, the needs of PLHIV differ depending on the phases of their disease. They are different when a person learns about his/her infection, change when a infected person lives without symptoms of AIDS and then radically change when AIDS develops.

Receiving information about HIV one's seropositive status is as a rule followed by fear and depression. Therefore, proper information about a positive HIV status is crucial to prevent an outburst of depression and/or a psychological crisis. Support from other PLHIV having similar experiences could be considered. In addition, communication with significant others should be facilitated, as conveying this information to them seems to be next to impossible.

In the phase of HIV without symptoms of AIDS, a patient has to acquire and accept a new health and social status. During that phase, treatment should be individualised as much as possible and psychological support offered during both general and specialised treatment. Support in maintaining or finding employment, other sources of income or housing is as important as medical interventions.

Eventually, during the phase when the first symptoms appear and ARV therapy is offered, PLHIV need intensive medical treatment, associated with intensive psychological support. The treatment team has to be prepared to manage organic and cognitive disorders.

c) Overcoming barriers / satisfying needs

Society

In a number of countries, changes in legislation and/or governmental policy are necessary to reduce stigma related to HIV (especially in health care), homosexuality, mental illness and drug consumers. Human rights of PLHIV, including rights to privacy and confidentiality about one's health status, should be protected formally and practically.

Raising awareness in society through the media (including TV movies) and through social campaigns should aim to reduce stigma and discrimination on the one hand, and prevent HIV transmission on the other.

Health care, staff

Detailed education on HIV/AIDS issues should be a part of medical school curricula. In addition, knowledge and skills of health care personnel need permanent up-grading. A comprehensive, multi-disciplinary training approach is recommended. E.g., psychologists should be aware of neuro-cognitive disorders among PLHIV, emerging after longer exposure. On the other hand, physicians who have to tackle somatic complications need more training related to psychiatric treatment and psychological help for PLHIV.

Health care, system

Re-organisation of existing HIV/AIDS testing/treatment systems is recommended. Diagnostic centres should be established to offer complex assessment of a person's health status, including neurological and psychiatric health. The centre would then be able to offer appropriate referral. Improvement of access to diagnosis, treatment and psychological care for disadvantaged groups should be considered for people from small towns/villages, homeless people and refugees.

Welfare system

Welfare support, i.e. better access to social services, may be crucial for a person's health status and the use of medical services. Special training on the problems of PLHIV should be provided for welfare staff.

NGOs

Development of and support for existing NGO's, training and education for NGO staff and volunteers, as well as decentralisation of their activities could help develop towards a permanent support network based on peer approach.

Needs, barriers and priorities - client perspective

Focus group discussions with PLHIV were carried out in all participating countries following a common protocol. The highest number of groups was held in the Czech Republic, followed by Poland with 4 groups, Estonia with 3 and Hungary with 2 groups. The remaining countries succeed to carry out just one focus group each. The number of participants varied from 4 to 11, depending on local circumstances. The focus group discussions were either taped or detailed notes were taken. As a rule, the discussion was led by one person assisted by another researcher. Anonymity and confidentiality were assured. On average, the discussions lasted about one hour and a half.

Table 11. Number of focus groups and their participants

Country	No.	Type of group	No. of participants	% of men
Czech Republic	8	MSM/heterosexual	37/8 (5-7 in each group)	100
Estonia	3	IVDU MSM Non-specific	6 5 4	100 100 50
Hungary	2	MSM Non-specific	8 7	100 0
Latvia	1	IVDU	7	70
Lithuania	1 or 2	IVDU	19	74
Poland	4	Not specific IVDU IVDU Non-specific	11 5 4 5	64 40 100 80
Romania	1	Non-specific	7	57
Slovakia	1	MSM + heterosexual	6	83
Slovenia	1	MSM	6	100

The participants were asked to discuss three major issues:

A) problems of people living with HIV and barriers in access to care,
B) needs of PLHIV, and
C) ways of overcoming barriers.

Like for staff groups, pilot focus groups were convened in Poland. The discussions were transcribed and then analysed. Two persons did the coding independently, then agreed upon common coding categories. Coding categories identified in the Polish study were then suggested as an analytical framework to other participating countries, and proved their utility in other settings.

Three levels were identified for analysing the problems and barriers:

- societal
- health care (institutional)
- individual

a) Problems

Societal level

Respondents from a number of countries claimed that a comprehensive policy on HIV/AIDS did not exist in their country, that national strategies exist on paper only, that the question has no priority whatsoever and that the financial resources available are inadequate.

Society is not well informed about HIV/AIDS, its causes, the risks associated with it, and the possibilities of treatment. Ignorance prevails, in addition to circulation of incorrect information. Stereotypes and myths disseminated by the media reinforce fear and social repulsion.

All these factors lead to stigmatisation and marginalisation of PLHIV. They are discriminated against, also in terms of their prospects in the labour market. Unemployment leads not only to material decline but also to isolation, lack of social relations and further marginalisation.

HIV is often associated with other issues that are unaccepted in society, such as drug use or homosexual behaviour. This may reinforce social exclusion and discrimination, also concerning access to health and social services.

Health care level

Due to their poor health status and diseases accompanying HIV, people living with HIV/AIDS should be in systematic contact with health services. However, from their perspective the health care system does not offer them any prospects for continuous care, with the exception of services specialised in HIV/AIDS. Access to other medical specialities is difficult and often next to impossible. Medical staff is not trained to offer help and care for infected persons.

Information about the possibilities of receiving appropriate care is very poor. Even those employed in HIV/AIDS-specialised services are not able to refer a patient to the appropriate mental health specialist, surgeon, dentist or gynaecologist.

Experiences with both general and specialist health care are not satisfactory at all. Their experiences with general health services in particular are discouraging. Staff in general health care services is incompetent where HIV-related issues are concerned, and ignorant about their mental health problems. Negative attitudes prevail. Participants in the focus groups cited numerous instances of stigmatisation and rejection. Some doctors simply refuse to admit patients with a positive HIV status, and do not offer them any alternative referral. Others put them on a waiting list or admit them as the last patients in a given day.

Confidentiality and intimacy are not respected. Often, one's HIV status is shown on medical documents available to all staff members, including drivers and receptionists. Sometimes, other patients can easily realise that a patient is sero-positive, which is very likely to lead to fear and panic among peer-patients.

The right to proper information is not respected either in the course of an ARV therapy. Patients have to sign a so called “informed consent” form, after having been offered very rudimentary and/or technical information. They understand that they will be deprived of treatment if they do not sign this consent form. They feel that signing this consent is aimed at protecting a doctor against legal liability rather than at preserving their rights.

In this context, PLHIV face a great dilemma concerning whether or not they should inform a physician about their status, for example when going to a dentist or for surgery. People who tried to be honest and reported their status often experienced discrimination or refusal to be admitted or cured. Those who do not give this information feel bad, confused, and unfair.

Individual level

Health problems associated with HIV/AIDS constitute a major burden for many infected individuals. They are under permanent stress, associated not only with each additional disease or infection, but also with the expectation of a deterioration of their immunodeficiency and the appearance of AIDS.

HIV damages not only one's physical health, but also affects the social standing of an infected person. Social networks are very likely to break down, not only due to others but also because a person may "expect" rejection. Many people break with their partner and are scared of having a new partner, their contacts with family become weaker or are completely severed.

The combined influence of deteriorating human relationships and disease affects a person's mental health, a fact which in turn deteriorates their quality of life, and the prospects of rebuilding their social life and finding regular employment. PLHIV suffer from low self-confidence and depression, have suicidal thoughts or even attempt suicide.

Indeed, some PLHIV are gradually excluded form the society. They live alone, lose social networks, employment, and may become homeless. Without financial resources they have to seek for income through begging or committing petty crimes, which reinforces social marginalisation and the risk of further health and social problems.

b) Needs

Regarding needs, the focus groups revealed at least two stages in which different needs have to be satisfied: the moment when one's HIV status is confirmed and the period during which needs evolve in the course of the disease. Three types of needs were identified:

- need for support in day-to-day life, including psychological support
- need for proper information
- need for adequate treatment and care.

Immediate psychological support is needed in association with HIV testing. Taking a HIV test comes with high levels of stress and fear, which may become a permanent feature while waiting for the results. Professional psychological support should be offered to those who come to be tested.

Such support is even more needed when the test shows a positive HIV status. In reality, psychological support is rarely given. People do not know where to go or how to behave, also as far as family relations and using health care services are concerned.

Therefore, in addition to psychological support, practical information and advise have to be offered, including better knowledge on HIV, ways of preventing its spread and where to go to get treatment and support if needed.

After overcoming a cognitive threshold and accepting their HIV status, PLHIV need further psychological support from their families, physicians and if possible from infected peers, through NGOs. They need support in adapting to their new health status, which often implies a new social position, including changing social networks and employment.

Both the infected person and those who live with him or her need more detailed knowledge on everyday issues such as sexual behaviour, hygienic standards, what to do in the case of injury, cooking etc.. Similar guidelines or advise is needed at the work place.

Finally, a need for adequate treatment was expressed, including HIV-specific treatment as well as treatment and care for everyday health problems (e.g. light injury, flu).

c) Overcoming barriers

The analytical framework adopted to analyse the problems and needs of PLHIV proved to be useful to assess their recommendations on how to overcome problems, remove barriers in access to care, and meet their needs.

Society

PLHIV seem to believe that national strategies on HIV/AIDS may have an impact on their lives. Some of them proposed adoption of such a strategy, some demanded its better implementation in practice. In addition, they called for improvement of legal regulations related to human and patient's rights of PLHIV and proper enforcement of existing legal regulations to reduce stigmatisation and discrimination. In parallel with legal measures and policies, educational efforts should be made to raise awareness and change attitudes in order to prevent stigmatisation and marginalisation of PLHIV.

Health care (staff)

Education for health care professionals is also crucial. Basic information on HIV/AIDS issues is needed, and should be followed by more detailed training on how to inform somebody about positive test results and how to treat health problems that are directly and indirectly associated with the infection. Special training should be offered on specific mental health problems that may appear in the course of disease, as well as on their prevention and treatment, and on psychological support.

Health care (system)

Limited access to different services constitutes an important barrier for PLHIV. Therefore, recommendations on access were made in all focus group discussions. Participants requested:

- improvement of access to free and anonymous HIV tests,
- improvement of access to treatment for all PLHIV/AIDS (for example, people from small towns/villages, homeless people),
- improvement of access to specialists (i.e. dermatologist, gynaecologist, surgeon, dentist),
- improvement of access to ARV therapy and new medicines,
- improvement of access to free psychological/psychiatric help in the each phase of HIV/AIDS.
- improvement of access to professional help for families of PLHIV
- improvement of access to information on health care centres, associations, NGOs, and support groups for PLHIV.

Recommendations regarding access are difficult to implement unless the whole system of care is revised and made more comprehensive. In addition to diversified medical treatment, the system should include welfare and legal support, support in finding employment and other services. It is of crucial importance to ensure a continuous flow of information between the different services, and efficient systems of referral.

NGOs

NGOs may play an absolutely crucial role in representing the interests of PLHIV, protecting their human rights, offering psychological support and advise, and helping them seek assistance and share experiences in dealing with everyday problems. Therefore, development of relevant NGOs and peer support groups should be one of the priorities of governmental and local actions concerning HIV/AIDS.

5. CONCUSIONS

Huge differences exist in HIV prevalence and incidence rates among participating countries, with figures100 times as high in one country than in another. Even in countries with similar routes of infection (e.g. intravenous drug use) the discrepancies can be considerable. This suggests that apart from the natural course of an epidemic, other factors external to the HIV issue play an important role. On the one hand there are the formal provisions and the institutional framework in the society in question, and on the other hand there are the social attitudes. Moreover, policy on social exclusion in general and the overall level of social marginalisation seem to be of crucial influence on the way in which an HIV epidemic develops.

Despite factors that are specific to individual countries, the Delphi survey showed an overall consensus among experts that access to health and welfare services constitutes a major need to be satisfied. PLHIV should be offered access to pre- and post-test counselling and support, followed by access to professional health care covering not only HIV/AIDS problems but also neurological, mental health, addiction and somatic health services. The need for social assistance was also emphasised, including assistance in occupational integration and legal matters.

Higher integration of care constituted another need expressed by experts from six out of nine countries. This means offering comprehensive care that meets the needs of PLHIV with a double or even triple diagnosis, who in addition suffer from social exclusion.

Experts from six participating countries agreed that psychological needs, including love, sexuality, intimacy, dignity and friendship, are next on the list of needs.

Most of the barriers to access to proper care identified in the Delphi survey were associated with needs of PLHIV that remain unmet. Moreover, cultural and social barriers came up. Negative public attitudes to PLHIV, combined with negative attitudes towards homosexuals, drug addicts and mentally ill people, constitute a societal barricade which is reinforced from both sides. Society excludes PLHIV, who in turn are scared of re-integration and ashamed of their status. They then isolate themselves and do not ask for the services they need unless their health status greatly deteriorates. Existing specialised services, with their fragmented care and poor systems of referral, discourage PLHIV from seeking help. specialised care is accessible to people living in large cities but for those who live in the countryside each visit to specialised services is a difficult expedition in terms of money and logistics.

Experts from all countries agreed that improving access to integrated care should be a priority. Co-operation between different services should be introduced. They recommended development of specific curricula in medical universities, as well as continuous inter-disciplinary training to ensure that sufficient staff with adequate qualifications is available.

Public awareness raising to reduce stigma and social exclusion is needed to improve the social position of PLHIV and facilitate their access to health and social services. On the other hand, development of peer-support associations and groups should be facilitated.

Focus group discussions with the staff of HIV services and PLHIV confirmed the Delphi survey results. Nevertheless, less emphasis was given to institutional reforms and more to societal aspects. Ignorance about HIV/AIDS, combined with discrimination and marginalisation, constitutes a major barrier, present both among the general public and social and general health services. Multiple stigma - related not only to HIV but also to mental health, homosexuality and drug addiction - leads to social exclusion and discourages PLHIV from attempting re-integration and regular use of services.

The needs of PLHIV evolve in the course of the disease. In the beginning they need psychological support in order to accept their new health status, as well as simple advise on how to live and behave and where to turn for help in their new situation. Later, overcoming fear and depression is crucial. In the years following infection numerous problems emerge, including mental health and social problems. When the first symptoms of AIDS appear there is an urgent need for intensification of care, both in medical and social terms.

Focus groups, unlike the Delphi process, provide opportunities for interaction of participants, and thus allow them to come to a consensus and formulate recommendations more precisely. At the societal level, changes in legislation are needed to overcome stigma and secure privacy and confidentiality. Public education and awareness campaigns are needed to change public attitudes.

Health care systems needs substantial changes, including better education on HIV/AIDS in medical schools and more elaborate training schemes for staff. Access to treatment must be increased not only for people living in smaller towns but also for other disadvantaged groups such as refugees and homeless people. Higher integration of health and welfare services was recommended, as well as support for NGOs.

In addition to conclusions that were common to both staff and PLHIV, the latter emphasised extremely poor access to general health services, where they suffer from discrimination, rejection and violation of human rights, including such basic rights as confidentiality, privacy and intimacy. In fact, in many countries they are simply deprived of access to basic services such as oral health, reproductive health, mental health and regular access to GPs. In their contacts with general health care services they face the dilemma of whether or not to admit to their status. Therefore, PLHIV are often reluctant to use these services and eventually turn to HIV/AIDS-specialised services when their health greatly deteriorates. This increases the burden on specialised services, which cannot be extended to satisfy all health needs of PLHIV all over the country.

Therefore, explicit national strategies are needed to overcome social stigmatisation, discrimination and marginalisation, in health and social services as much as in the labour market. Development of NGOs in that area should be facilitated not only to offer peer-support and advice, but also to speak out on behalf of discriminated minorities.