

Operational Research

**Prevention, care and needs of people living with
HIV/AIDS**

NGO KAPHA

Prishtina

Supported by Global Fund Project

Prevention, care and needs of people living with HIV/AIDS

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through the seventh round of Global Fund

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ACKNOWLEDGMENT

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We express our gratitude to all individuals who are interviewed to gather all the processed data in this research such as: Ministry of Health – Office for HIV/AIDS, Division for Public Health, Pharmacy Department, Department of health Services, Procurement Department and Human Resources Division, than the Clinic Infection, Genecology Clinic, Dental Clinic, National Centre of Blood Transfusion, Family Health Centres - FHC, and National Institute of Public Health – NIPH. Moreover, a special gratitude is addressed to all persons living with HIV/AIDS, whose names will not be mentioned in this research for security reasons and privacy protection. Through their responses they gave a very realistic and objective view about the services that they receive; needs they have and barriers they face in acquiring these necessary services.

This research would have been impossible to realize without the tireless commitment and contribution of Dr. Sami Rexhepi and Dr. Magbule Vata-Rexhepi who contributed to the development of the questionnaire and interviewing the research participants.

M.Sc. Violeta Zefi,

Research Coordinator

Abbreviations

AIDS Acquired immune deficiency syndrome

KAPHA Kosovar Association of Peoples living with HIV/AIDS

ART Antiretroviral therapy

GFATM The Global Fund to Fight AIDS, Tuberculosis and Malaria

HIV Human immunodeficiency virus

HO Operational Research

IEC Information, Education and Communication

IPH The national Institute of Public Health

MH Ministry of Health

NJMP Project Management Unit

PEP Post-Exposure Prophylaxis

QKUK University Clinical Center Kosova

QMF Centre for Familiar Medicine

1. PREFACE

Association of Persons living with HIV/AIDS, which is the only organization in Kosovo offering services to persons living with HIV/AIDS (providing psycho-social services and medical consultation, advocacy and lobbying, development and distribution of IEC materials for people living with HIV/AIDS and for the general population, etc.), is contracted by the Project Management Unit - PMU and Global Fund to fight AIDS, Tuberculosis and Malaria - GFATM for HIV at the Ministry of Health - MSH. Association of Persons living with HIV/AIDS through its very professional and experienced researchers has conducted a research study called: *Operational Research on Prevention, Care and Needs of people living with HIV/AIDS*.

The report contains findings from the Operational Research - OR requested by the Unit Project Management of GFATM for HIV in Ministry of Health within the Ob. 4 - SDA 4.2.1 of project KCM for HIV/AIDS and TB and implemented by the Association of people living with HIV/AIDS.

The aim of the research was:

To conduct an operational research for identifying prevention, care and needs of people living with HIV/AIDS.

The research aimed to collect the opinion of three groups: decision makers, health workers and people living with HIV/AIDS. The specific approach of methodological research is designed for each of these groups. This is the best way to address to the requirements of research, goals, issues and questions previously identified as very important for each of the targeted groups.

2. EXECUTIVE SUMMARY

Based on existing data and classification system according to UNAIDS, Kosovo is considered as a country with low scale of HIV epidemic by less than 1% of the total population and less than 5% of groups with high risk rate. The region of South Eastern Europe is characterized by the highest rate of growth of HIV epidemic in the world which can have an impact on the epidemic's development in Kosovo. For this reason, information on prevention, care and needs of people living with HIV/AIDS are basic in order to respond to the needs for care and support for persons living with HIV/AIDS. Also, not very much is known about the many challenges - including stigma and discrimination - that people living with HIV/AIDS face. Low scale interventions will allow a closer understanding of prevention, care and their need for support and will develop a comprehensive range of high quality services that are adapted to their needs.

The entire research is a qualitative type and is focused on three groups. Research with the first group, consisting of 14 persons living with HIV/AIDS, was conducted by individual structured interviews. The second group consisted of 16 health workers and the interviews were conducted individually. While the third group consisted of 6 persons was conducted with the focus group.

Findings

Findings from the overall analysis of interviews with people living with HIV/AIDS

Graph 1. Distribution by age group

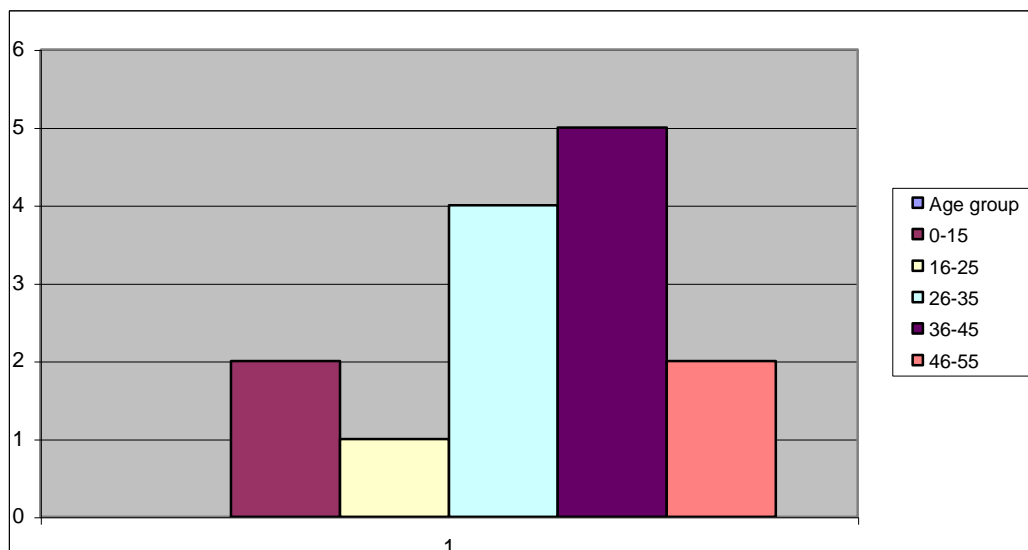


Table 1. Geographic distribution

<i>Region</i>	<i>Number</i>
Peja	2
Prishtina	4
Deçan	1
Prizren	4
Obiliq	1
Podujeva	1
Gjakova	1

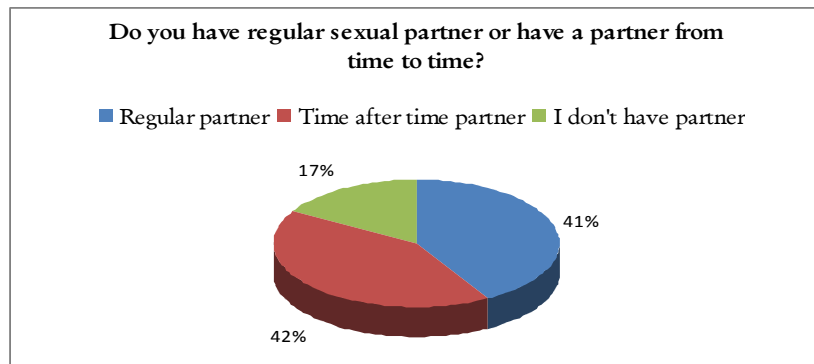
Knowledge about HIV/AIDS

From the analysis of the interviews with the participants, in 100% of the cases, it is understood that they have knowledge about the disease: they know that HIV infection is incurable, know the ways of transmission, know the importance of using protective measures, and know the importance of receiving ART therapy.

Use of protective measures and sexual partners

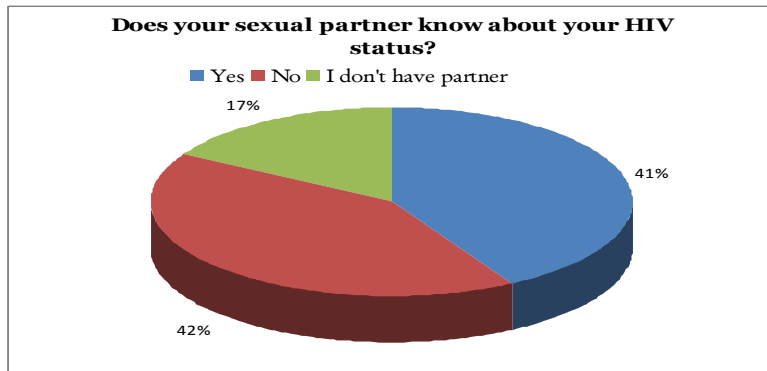
On the question of whether you have regular sexual partner or have a partner from time to time, 41% declared that they have regular partner, 42% have stated a time after time partner, while 17% stated that they have no sexual partner.

Graph 2. Do you have regular sexual partner or have a partner from time to time?



On the question whether your sexual partner know about your HIV status, 41% stated that they have informed their sexual partner about HIV status, 42% did not informed their sexual partner of HIV status, while 17% have stated that they have no sexual partner.

Graph 3. Does your sexual partner know about your HIV status?

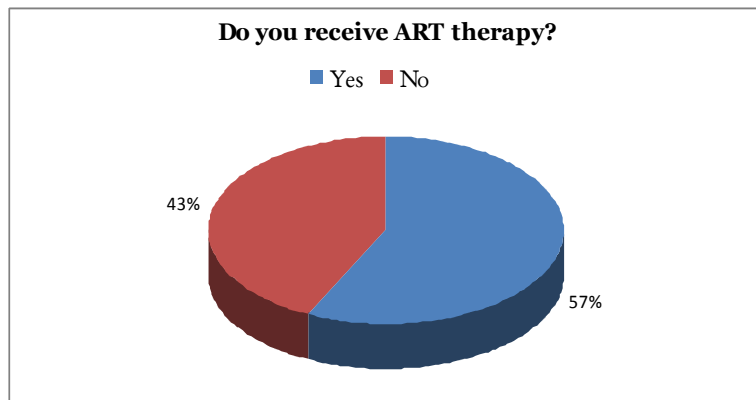


Challenges related with Antiretroviral Therapy

Fifty-seven percent (57%) of the participants have declared that they are in ART therapy, while 43% do not take therapy. In percentage who does not take therapy, a therapy was not recommended by a doctor to four persons, and one person doesn't want to take ART therapy despite that he needs the therapy. Fear that others will understand it is infected with HIV has made this person not to start taking ART Therapy.

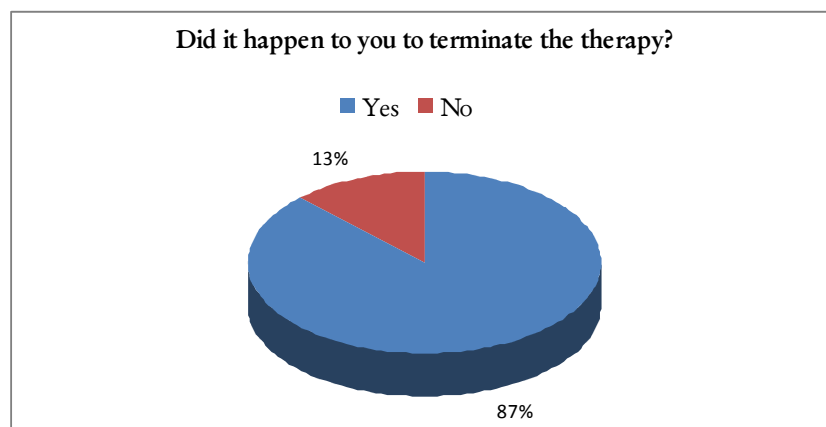
All participants who are in therapy have declared that they take the therapy regularly.

Graph 4. Do you receive ART therapy?



Eighty-seven percent of people in therapy have discontinued therapy since they have begun taking and have restarted again, and only 13% of them have not stopped the therapy ever.

Graph 5. Did it happen to you to terminate the therapy?



Creating the conditions for psychological support

All participants have declared that they need psychological support, and they see this as an opportunity to refer the situation in which they are and difficulties they're passing through. They have declared that they are supported by the Association of People Living with HIV/AIDS.

Findings from the overall analysis of interviews with decision makers

Existing programs for HIV/AIDS and their effects

Participants have declared that the programs on HIV/AIDS are based on the strategy of HIV/AIDS 2009-2013. Regarding the effects of programs on HIV AIDS the decision makers have stated that they are not sure on the effects of the training programs, but they believe that

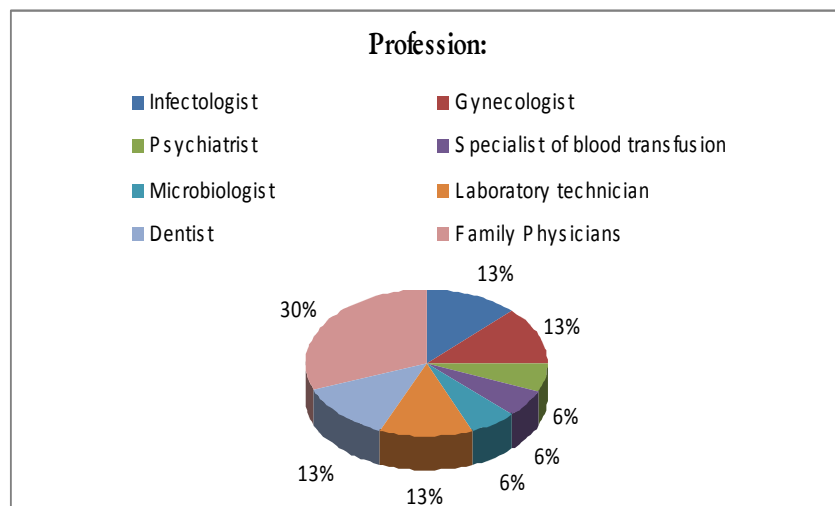
most the offered trainings for health workers, teachers, and the education of students about HIV/AIDS have raised the level of awareness about HIV/AIDS.

Funds for the care of people living with HIV/AIDS

Decision-makers have declared that funds for the care of people living with HIV/AIDS exist, but according to them the separate budget line for HIV/AIDS is lacking. They have declared that, within the Department of Pharmacy the budget for therapies and tests exists.

Findings from the overall analysis of interviews with health workers

Graph 6. Profession

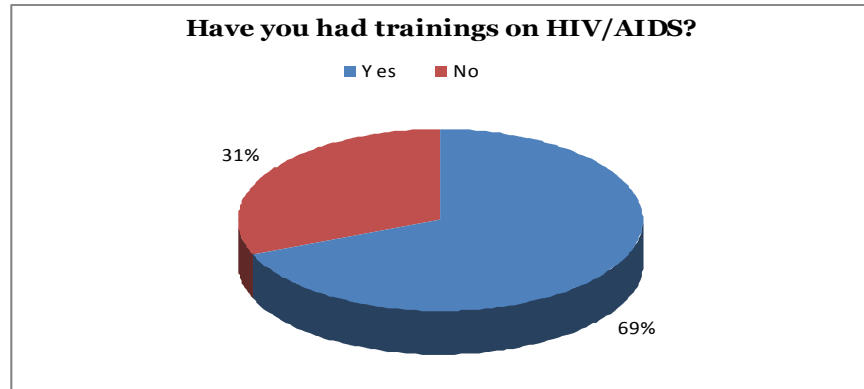


Protective measures at work and their use

On the question: do you have protective means which you use at your daily work and do you always use them, 100% of the cases have declared that they use protective measures when needed, respectively in all cases when it may come to the contact with causes of infection. Also, in 100% all cases have stated that they did not refuse working even when they did not have protective measures.

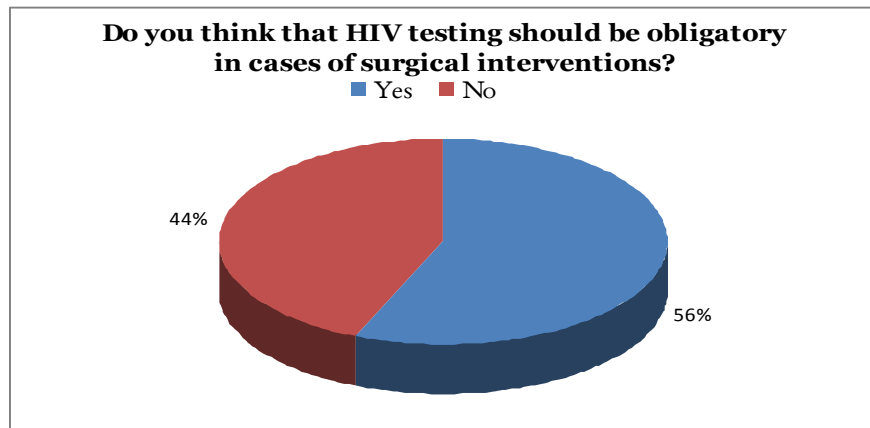
69% of cases reported to have had trainings on HIV/AIDS, while 31% of cases have stated that they had no training on HIV/AIDS.

Graph 7. Have you had trainings on HIV/AIDS?



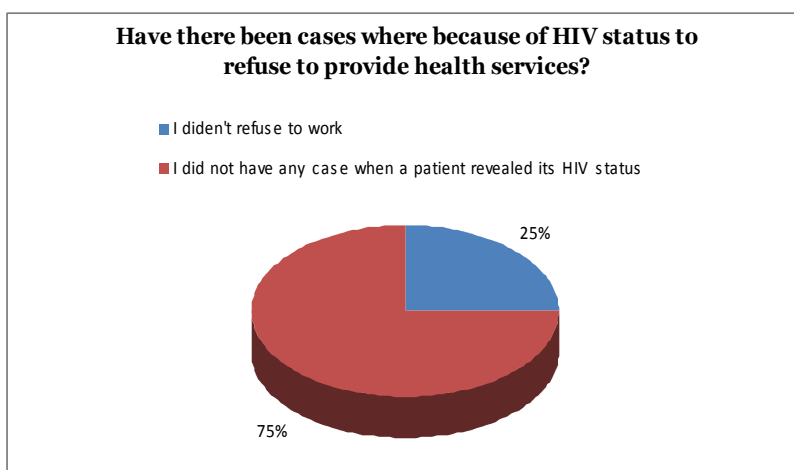
On the question whether the HIV test should be obligatory in cases of surgical interventions, 44% of cases have declared that the test should be obligatory, 56% of cases have stated that there should not be obligatory.

Graph 8. Do you think that HIV testing should be obligatory in cases of surgical interventions?



On the question whether there were cases when due to the HIV status you refused to offer medical services, 25% of the cases declared that they didn't refuse to work, whereas 75% of the cases have declared that they didn't have the opportunity when any patient discovered HIV status, but they also stated that they wouldn't refuse to offer medical services even in cases when the patient declares HIV status.

Graph 9. Have there been cases where because of HIV status to refuse to provide health services?



On the question: do you think that the information about the patients HIV status should remain confidential, 100% of the cases stated that the information about the HIV status should remain confidential.

3. OBJECTIVES

The main objective of this research was:

- To provide information on the needs of people living with HIV/AIDS;
- To identify the level of knowledge and readiness to prevent HIV/AIDS;
- To identify the level of knowledge about self-care;
- To determine the needs, ways and forms of completion.

4. METHODOLOGY

This research project was realized by conducting structured interviews with persons living with HIV/AIDS and health workers and for the decision makers a focus-group was organized. Firstly the targeted groups were identified and then they were contacted to be interviewed.

Qualitative research:

- Semi-structured focus groups with decision makers;

- Structured interviews with health workers and
- Structured interviews with persons living with HIV/AIDS.

Sample:

- 14 persons living with HIV/AIDS;
- Focus group with decision makers - 6 persons and
- 16 health workers.

People living with HIV/AIDS – the total number of interviews conducted with persons living with HIV/AIDS is 14 persons. The interview was focused on getting information about prevention, care and needs of people living with HIV/AIDS. The way of receiving information from this target group was based on structured interview, run by the interviewer, who could provide clarity in the formulation of questions. Interviews were conducted face to face.

Health care providers and decision makers – 16 health workers were interviewed and a focus group was conducted with the decision maker. Through the interviews with health workers extensive information were received about needs evaluation and services provided to persons living with HIV/AIDS, then the use of protective measures, etc. On the other hand, the focus group organized with decision makers has gathered information on prevention programs for HIV/AIDS in Kosovo, services which are offered for people living with HIV/AIDS, etc.

Method of Interview:

The research method consisted of deep interviews, which were structured and were conducted with persons living with HIV/AIDS and health workers, whereas the focus group was organized with decision makers. The overall size of the sample is determined by two factors: the recommendation of the research group of this project and the cost.

Starting from the fact that margins of mistaking are calculated and are applicable only to quantitative research, in this research which is qualitative, the margin of mistaking cannot be applied. While, the reliability of the answers is 95%.

5. CHALLENGES/DIFFICULTIES

The difficulty in access to all HIV infected people so far in Kosovo was because some of people with HIV are not registered at the relevant institutions (after are identified with HIV), whereas one part of people with HIV have died.

6. ETHICAL CONSIDERATION

All participants in the research were assured of keeping confidentiality and that data extracted from the interviews would remain confidential. Any person who participated in the research was given a preliminary explanation of the purpose of research and its importance in order for them to take a decision whether to participate in research or not.

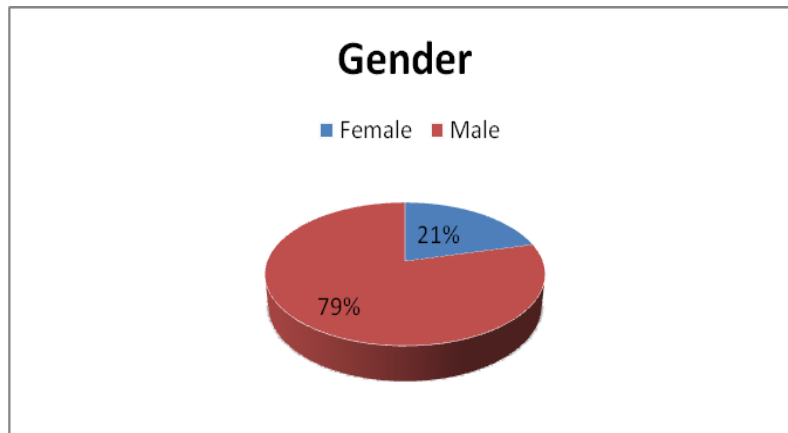
7. SUMMARY

Findings from the overall analysis of interviews with people living with HIV/AIDS

Demographic data of persons living with HIV/AIDS

Gender

Graph 1. Gender



Distribution by age group

Graph 2. Distribution by age group

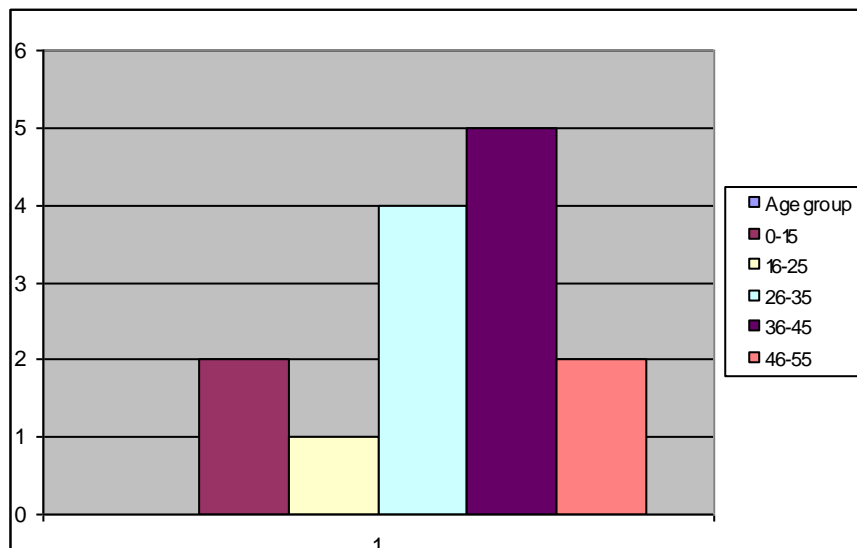


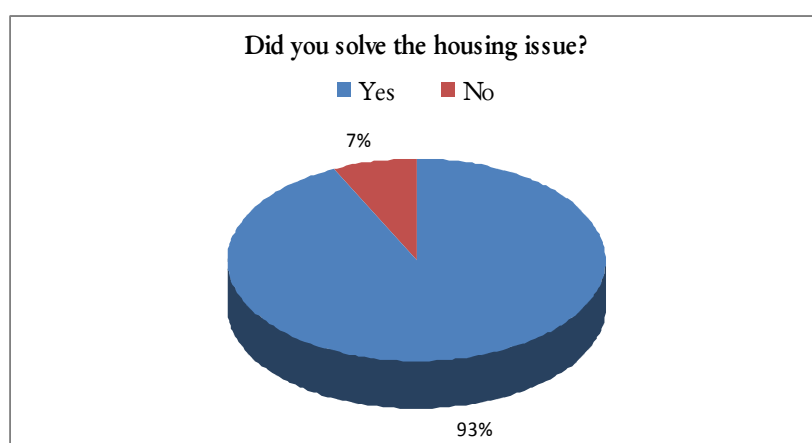
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Housing issue

Ninety-three percent of the cases reported that they solved the housing issue, while 7% of cases reported that do not have good housing conditions.

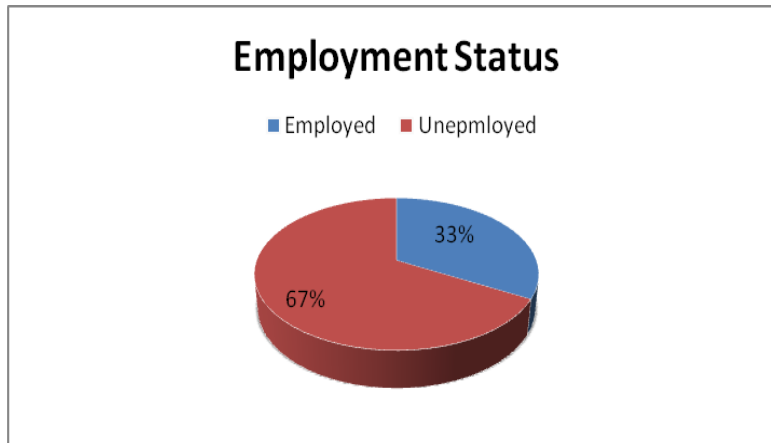
Graph 3. Did you solve the housing issue?



Employment Status

Thirty-three percent of participants are employed, while 67% of participants are unemployed.

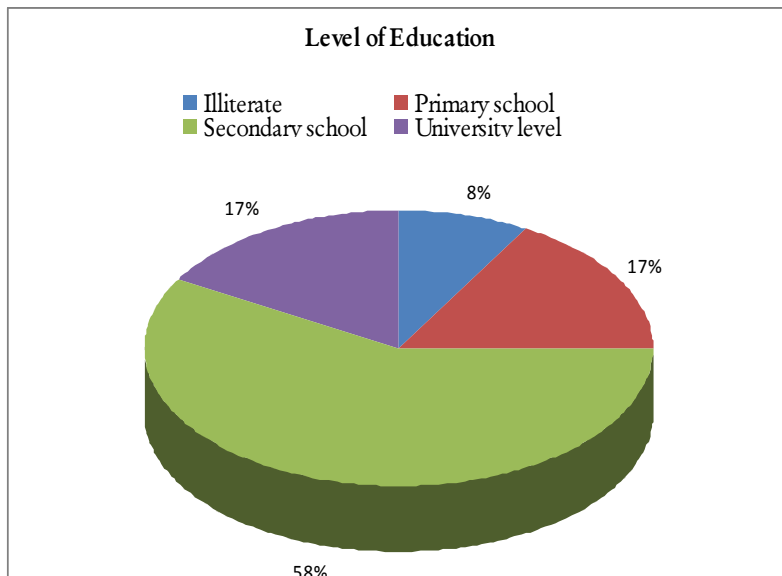
Graph 4. Employment Status



Level of education

8% of the participants are illiterate, 17% of participants had completed primary school, 58% secondary school and 17% the university level.

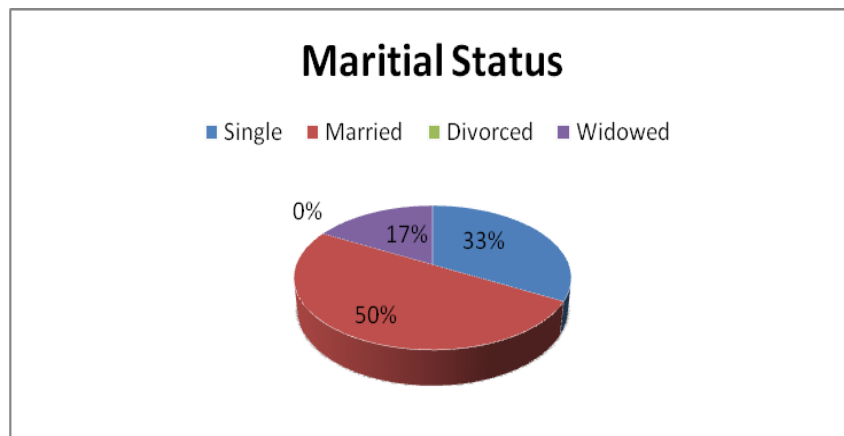
Graph 5. Level of education



Marital Status

Thirty-three percent of participants are single, married, 50% are married, while 17% of the participants are widowed.

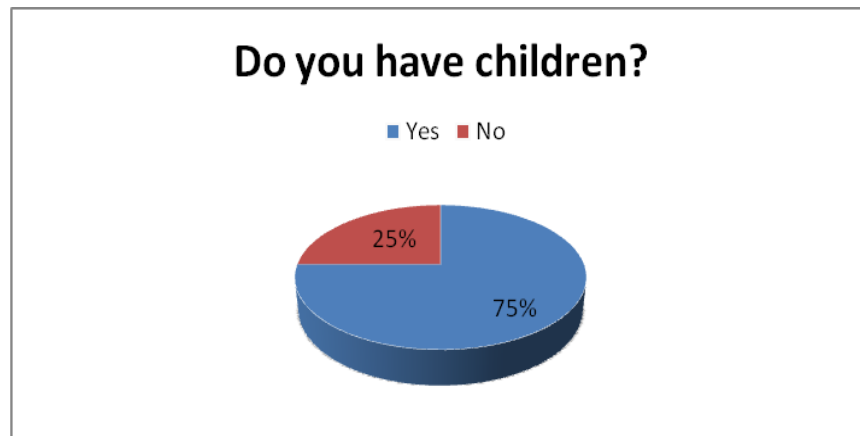
Graph 6. Marital Status



Do you have children?

Seventy-five percent of participants have children, while 25% of participants do not have children.

Graph. 7. Do you have children?



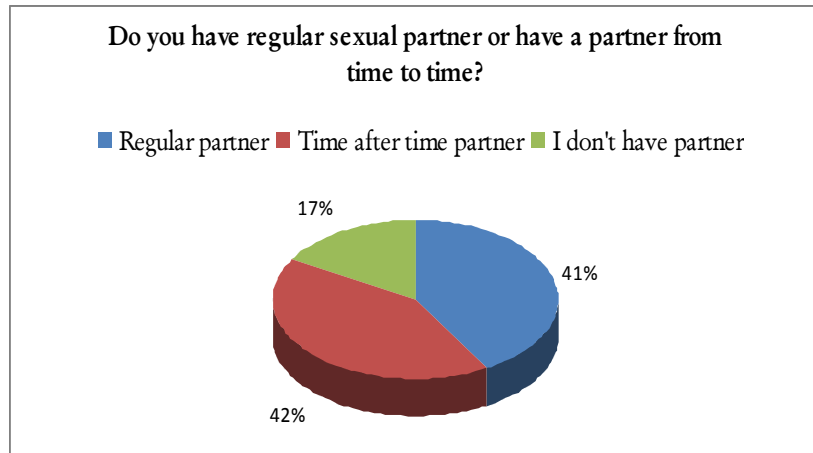
Knowledge about HIV/AIDS

From the analysis of the interviews with the participants, in 100% of cases it is understood that they have information about the disease: they know that HIV infection is incurable, know the ways of transmission, know the importance of using protective measures, and they know the importance of receiving ART therapy. They also declared that information about HIV/AIDS was received through the television as well as IEC materials which they have received at the “Association of people living with HIV/AIDS”.

Use of protective measures and sexual partners

On the question of whether you have regular sexual partner or have a partner from time to time, 41% declared they have regular partner, 42% have stated a time after time partner, while 17% stated that they have no sexual partner.

Graph 8. Do you have regular sexual partner or do you have a time to time partner?



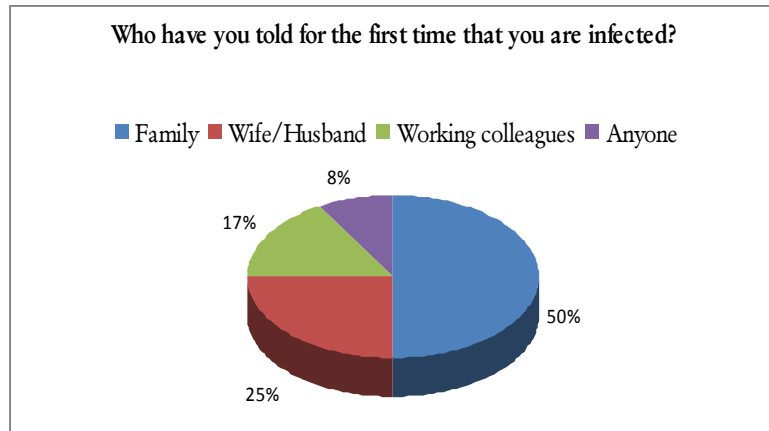
All participants who have regular sexual partner or from time to time partner have declared to use protective measures during sexual relationships.

Disclosure of HIV status

On the question that to whom you told for the first time whether are infected with HIV, 50% of participants stated that they have told their family, 25% their wife/husband, 17% their working colleagues, while 8% stated that they did not have told to anyone.

Sharing of information with the wife/husband or the sexual partner is very important for health protection and prevention of infection by HIV. The above mentioned declarations suggest that there remains much to be done on consultation services to persuade the infected people to inform on time their sexual partners.

Graph 9. Who have you told for the first time that you are infected?



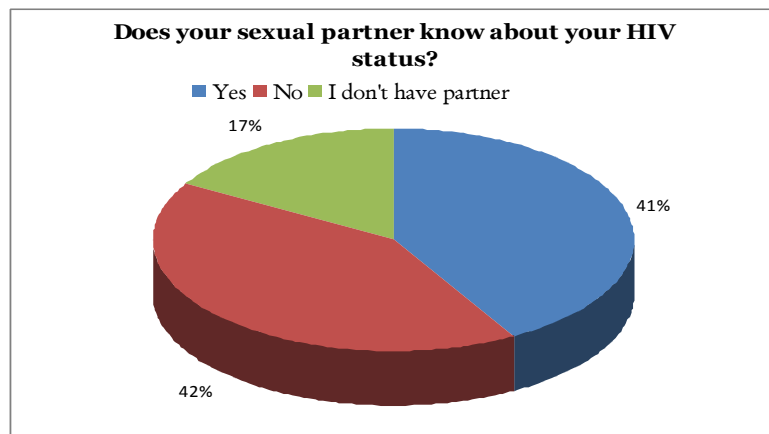
Story 1. It has been my wife who first got to know about my HIV status, within ten days that I realized I have informed the wife.

On the question: does your sexual partner know about your HIV status, 41% declared that they have

Informed their sexual partner about HIV status, 42% did not informed their sexual partner of HIV

status, while 17% have stated that they don't have sexual partner.

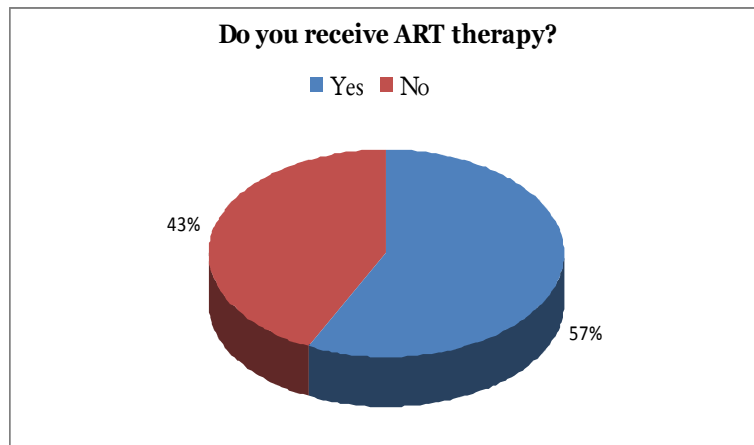
Graph 10. Does your sexual partner know about your HIV status?



Challenges associated with antiretroviral therapy

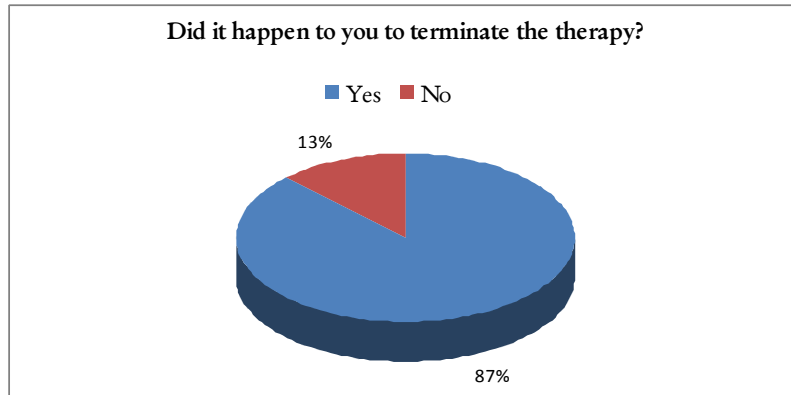
Fifty-seven percent (57%) of the participants declared that they are in ART therapy, while 43% do not receive therapy. The percentage who does not receive treatment, therapy was not recommended by a doctor to four persons, and one person doesn't want to take ART therapy despite that they needs the therapy. Fear that others will know it is infected with HIV has made this person not to start taking ART Therapy. All participants who are in therapy stated they receive the therapy in regular bases.

Graph 11. Do you receive ART therapy?



Eighty-seven percent of people in therapy have terminated therapy since they have started to take it and have restarted again and only 13% of them have not stopped therapy.

Graph 12. Did it happen to terminate the therapy?



Some of the reasons for termination of therapy:

- There was no therapy. Due to lack of therapy for different periods during treatment, they are forced to stop and resume therapy;
- Termination of therapy with self-desire.

Story 2. Since I started the therapy, I stopped twice due to lack of therapy.

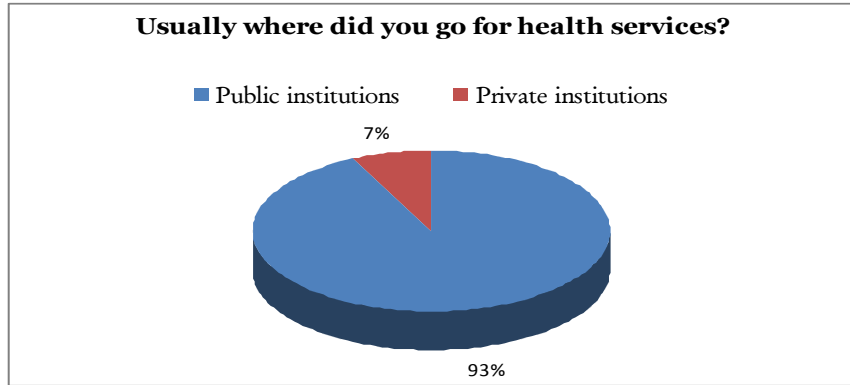
All participants who are in ART therapy declared that at the beginning of therapy they have received adequate information from the doctor about the use of the therapy and were informed about possible side effects. In addition, 100% of the cases have declared that before beginning the therapy they've conducted laboratory tests in order to understand the values (CD4 and viral load) which determine when to start therapy.

Regarding the information about the results of laboratory analysis, all cases (100%) declared that they were never informed for the results of laboratory analysis by the institution which deals with their medical treatment.

On the question of how many times a year they have medical examination, 100% of cases declared to have a medical examination twice a year, when they go for laboratory analysis, whereas according to the needs within a year they do medical examinations. Ninety-three

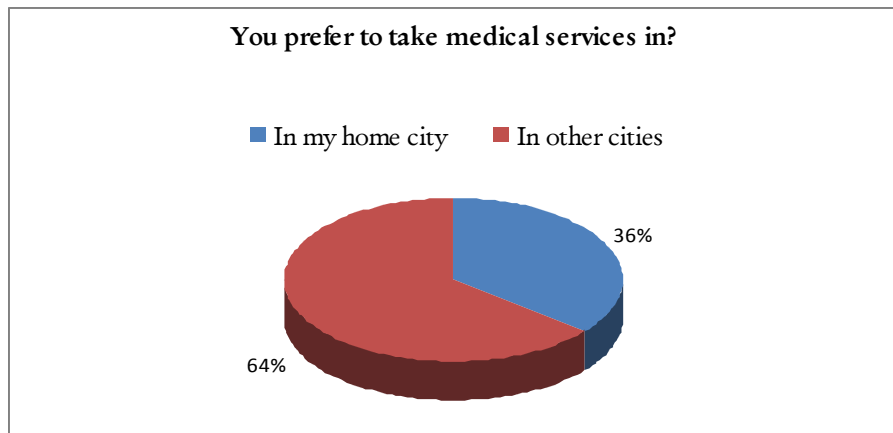
percent of participants declared that usually for health services they go to public institutions, whereas only 7% go to private institutions to receive health services.

Graph 13. Usually where did you go for health services?



On the question: do you prefer more to take medical services in your city or in other cities, 36% declared that they prefer to take medical treatment in their home cities, whereas 64% declared that they prefer to take medical treatments in other cities.

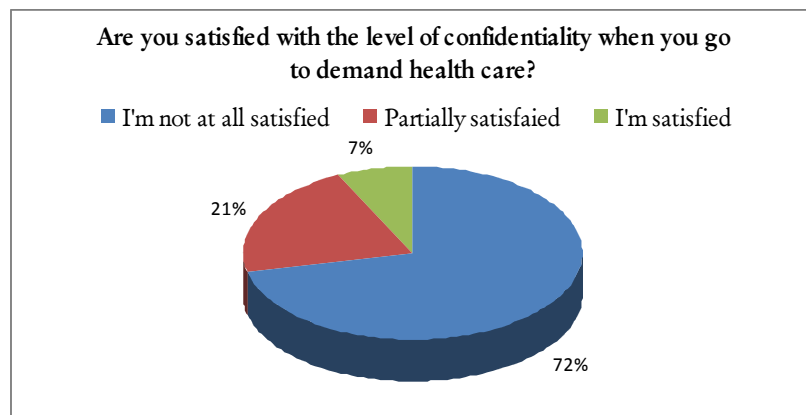
Graph 14. You prefer to take medical services in?



The level of confidentiality in health institutions

Seventy-two percent of cases have declared that they are not at all satisfied with the level of confidentiality when going to get any service in health institutions, 21% stated that they are partially satisfied, while 7% stated that they are satisfied with the level confidentiality in health care.

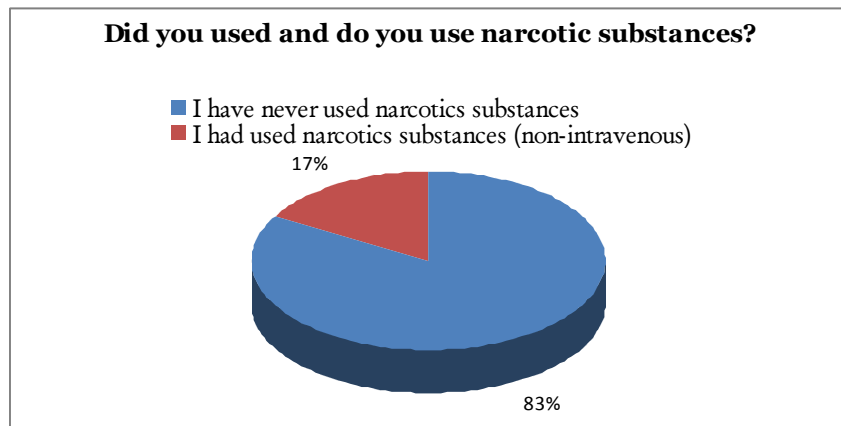
Graph 15. Are you satisfied with the level of confidentiality when you go to demand health care?



Use of narcotic substances

On the question of whether you used narcotic substances in the past or now, 83% of cases have declared that they have never used narcotic substances, while 17% of cases have stated that earlier had used narcotic substances (non-intravenous).

Graph 16. Did you used and do you use narcotic substances?



Creating the conditions for psychological support

All participants declared that they need psychological support, and they see this as an opportunity to refer the situation in which they are and the difficulties they're passing through. They have stated that this support they receive at "Association of People Living with HIV/AIDS".

Story 3. Association of People Living with HIV/AIDS is the only place where I get services with pleasure and I feel free to discuss the situation in which I am passing through.

Relationships with family members and their care towards persons living with HIV/AIDS

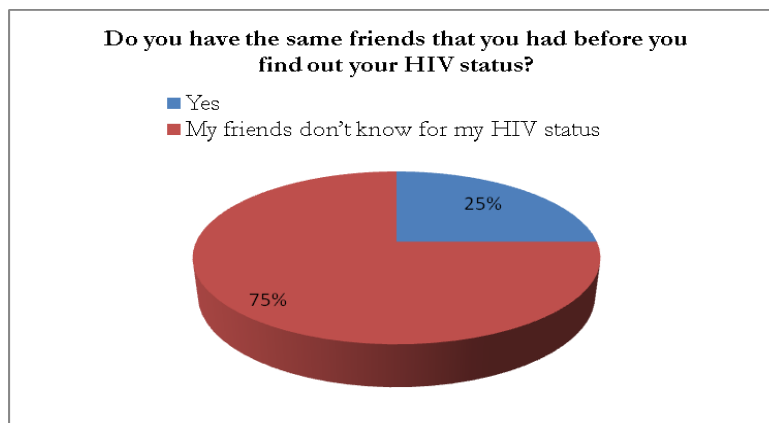
Ninety-three percent of cases have declared that they live with their families, while only 7% live alone. The fact that most of the people living with HIV continue to live with their families or their partners shows that within the close circle of family the level of support continues to be strong. Number of cases that have informed family for their HIV status, have stated that their family members care for them and that the level of communication is good.

Only two cases have declared that their members of the wider family created distance with them since they find out their HIV status and don't want any more to contact with them.

Relationships and communication with friends

One hundred percent of the cases reported to have good relationships and a good level of communication with their friends. 25% have same friends as they had before finding out their HIV status, while 75% stated that their friends don't know about their HIV status.

Graph 17. Do you have same friends that you had before you find out your HIV status?



Findings from the overall analysis of the interviews with decision makers

Decision makers are an important group for the life of people living with HIV/AIDS and of their life quality as well. Due to the specifics of the analyzed phenomenon, this focus group has helped to understand developments within the respective framework which regulates treatment of HIV/AIDS in Kosovo.

Existing programs for HIV/AIDS and their effects

Participants have declared that the programs on HIV/AIDS are based on the “Strategy of HIV/AIDS 2009-2013”. Regarding the effects of the programs on HIV/AIDS, they declared to be not sure on the effects of training programs but they believe that the trainings for health workers, teachers and the education of pupils about HIV/AIDS have raised the level of consciousness about HIV/AIDS.

They are focused on testing centres in order to enhance their functionality. They also declared that testes are provided regularly, despite the fact that short deadlines of sustainability sometimes shows problems in supply. According to them, this problem is resolved with a one year contract to supply with tests every six months. They also emphasized that the development plan of the laboratory for viral load and CD4 is not in plan due to the lack of financial means but clients are not left without these analyses because these analyses are sent in France. A problem that they highlighted is the late submission of requests for tests and laboratory analysis.

Health workers in the working places

Health workers are not left without protection means in their working places.

How media cover the area of HIV/AIDS

Participants of the research declared that the interest of media for HIV/AIDS is focused mainly during the international day of HIV/AIDS. Generally speaking, the interest of journalists on HIV/AIDS is very little.

Funds for the care toward persons living with HIV/AIDS

Decision makers declared that there are funds for the care of persons living with HIV/AIDS, but according to them, there is no budget line for HIV/AIDS. They declared that, within the

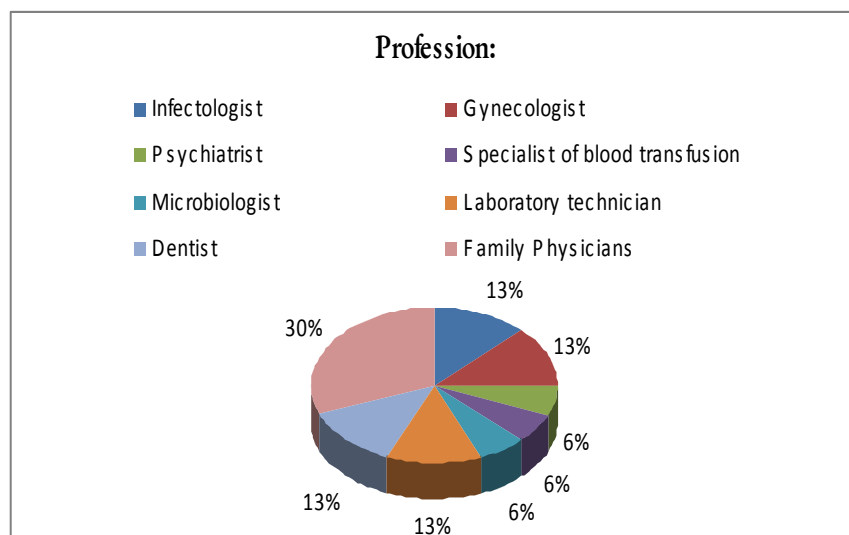
Department of Pharmacy the budget for therapies and tests exists. They also mentioned that there have to be more funds for prevention of HIV/AIDS.

Needs of people living with HIV/AIDS

Participants of the research declared that existing requirements for therapy are fulfilling, but the needs for new medicaments might present a problem due to the existing procedures.

Findings from the overall analysis of the interviews with health workers

Graph 18. Profession

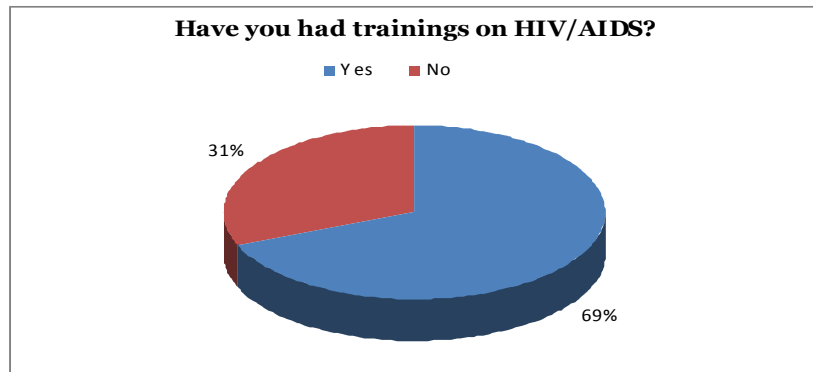


Protective measures at work and their use

On the question: do you have protective means which you use in your daily work and do you always use them, 100% of cases stated that they use protection measures when they are needed, respectively in all cases when it may come in contact with cause of infection. Furthermore, in 100% of all cases declared that they have not refused to work even when they didn't have protective measures.

69% of cases declared to have had trainings about HIV/AIDS, while 31% of cases have stated that they had no trainings on HIV/AIDS.

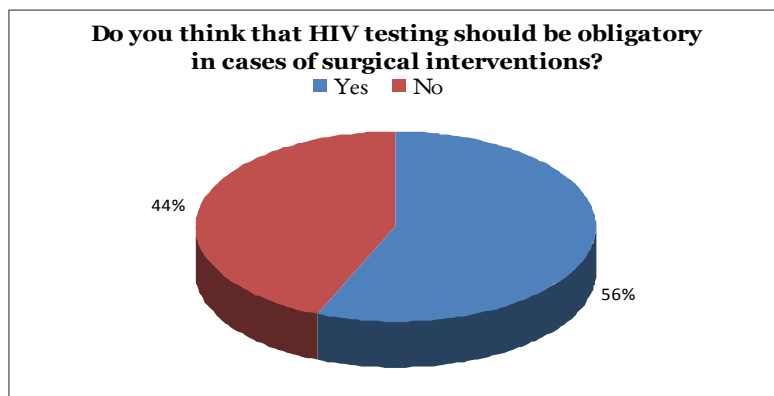
Graph 19. Have you had trainings about HIV/AIDS?



On the question whether you think that the HIV test should be obligatory in cases of surgical interventions, 44% of cases have declared that the test should be obligatory, 56% of cases stated that it should not be obligatory.

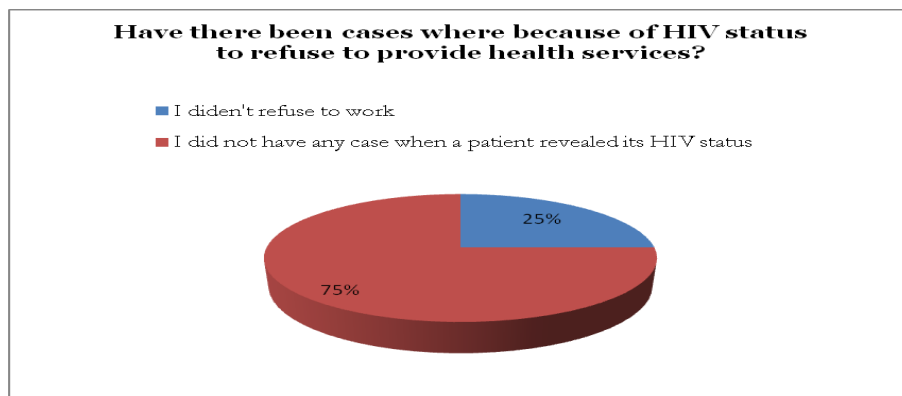
Story 4. I think that it should be obligatory testing before surgery interventions, in order to be better protected and there is a possibility to select ways of intervention when there is less bleeding (Dentist).

Graph 20. Do you think that in cases of surgical interventions the HIV test should be obligatory?



On the question whether there were cases when due to HIV status you refuse to provide health services, 25% of cases declared that they have not refused to work, while 75% of cases declared that have not had a chance that any patient to reveal its HIV status, but they also declared that they would not refuse to provide health services even when the patient declares its HIV status.

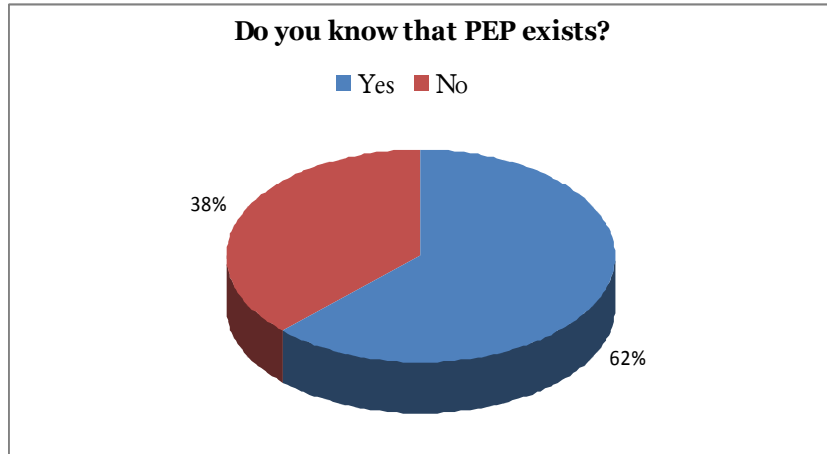
Graph 21. Have there been cases where because of HIV status to refuse to provide health services?



On question: do you think that the information about patients' HIV status should be saved, 100% of cases have declared that the information about patients' HIV status should remain confidential.

On the question whether you have information that PEP exists (Post-Exposure Prophylaxis), 62% of participants declared that they have information that PEP exists, whereas 38% declared that they have no information that PEP exists.

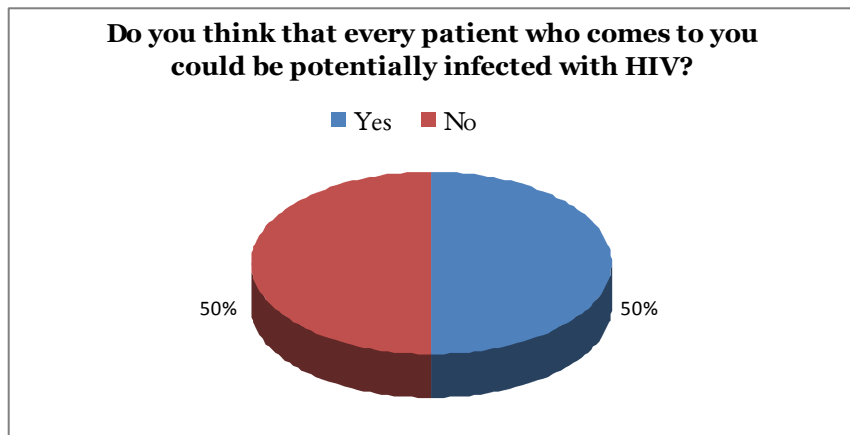
Graph 22. Do you know that PEP exists?



On the question how you eliminate remaining residuals which are created during your work, 100% of cases have declared that they have safe boxes in which they throw remaining residuals created during the work, and the further management of residuals is done by the relevant institution.

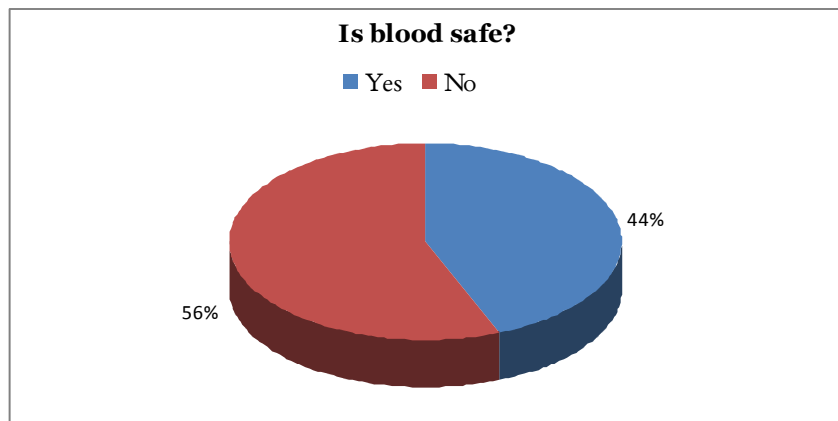
When asked do you think that every patient who comes to you could be potentially infected with HIV, 50% declared that they see each patient as potentially infected with HIV, while 50% stated that they do not see as a potential patient for HIV.

Graph 23. Do you think that every patient who comes to you could be potentially infected with HIV?



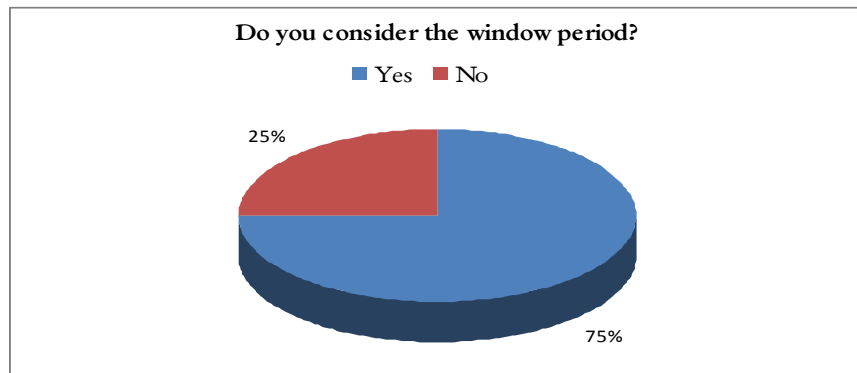
On the question of whether the blood is safe (for transfusion), 44% declared that the blood is safe, while 56% have stated that the blood is not safe.

Graph 24. Is blood safe?



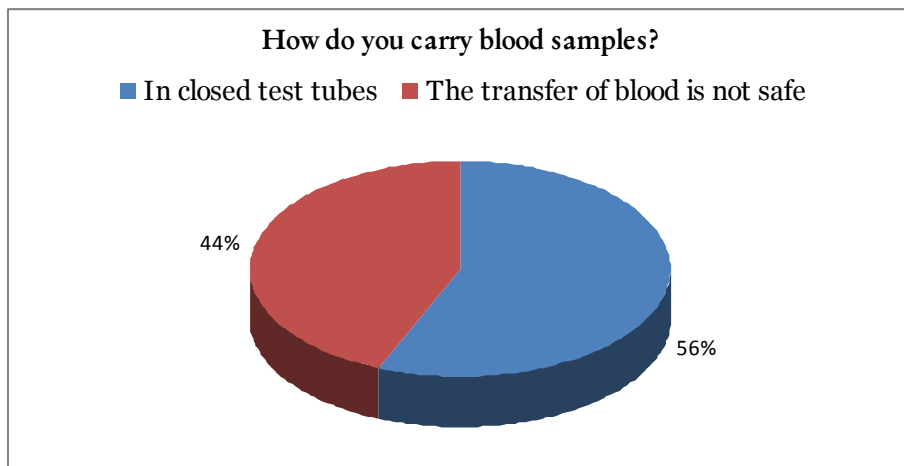
On the question whether you consider the window period of HIV, 75% declared that they have knowledge about the window period, while 25% stated that they have no knowledge about the window period.

Graph 25. Do you consider the window period?



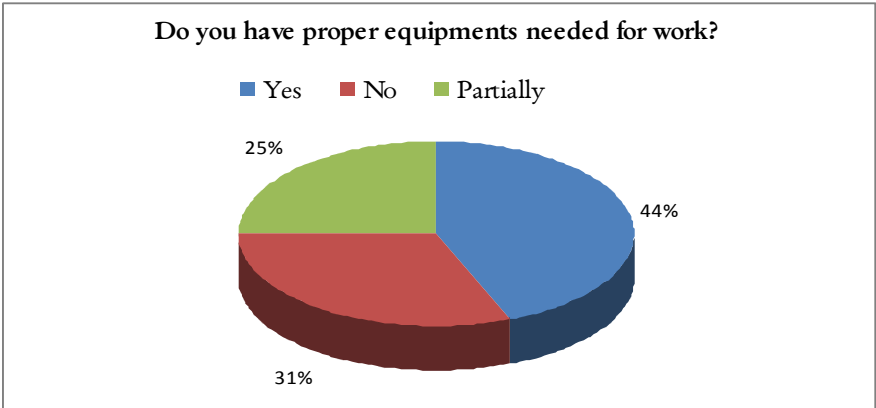
On the question how do you carry blood samples, 56% of cases have stated that blood transfer is done in closed test tubes, while 44% declared that the transfer of blood is not safe?

Graph 26. How do you carry blood samples?



On the question of whether you have proper equipments required for work, 44% of participants declared that they necessary equipment for work, 31% declared that they have no equipment required for work and 25% declared that they have partially equipments for work.

Graph 27. Do you have proper equipments needed for work?



8. CONCLUSIONS

The level of knowledge about HIV/AIDS (ways of transmission, use of protective measures, and the importance of taking the therapy) among people living with HIV/AIDS is satisfactory.

Needs of people living with HIV/AIDS, based on the research, are:

- Systematic controls, as well as information about the results of laboratory analysis;
- Offering of ART therapy without interruption, respectively better and in time management of the therapy;
- Taking health services and other services as all other persons without prejudices.

In generally health workers have declared that they always use protective measures, and never (those who have had the opportunity) have not refused to offer health services to people living with HIV/AIDS.

The results of this research show the need for consciousness and information of health workers about the rights of people living with HIV/AIDS and the obeisance of these rights.

Based on the data from the participants of the research it is obvious that the need for cooperation between different sectors that provide services to persons living with HIV/AIDS, in order to increase as much as possible the life quality of these persons.

9. RECOMANDATIONS

- Improving government policies in order to provide greater support to people living with HIV/AIDS;
- Providing support from all relevant sectors to face stigma and discrimination which is a major obstacle for the benefaction of various services;
- Better and in time management of the therapy and laboratory analysis for persons living with HIV/AIDS;
- Training of health workers and strengthening the connection between the relevant clinics;
- The results of this study highlight the need for closer cooperation between key institutions dealing with the treatment, care and needs of people living with HIV/AIDS;
- Civil society should advocate on the basis of concrete data in order that these data to help in the formulation of policies and programs which take into account the real needs of people living with HIV/AIDS;
- Since the major part of the people living with HIV/AIDS live together with their families, there should compose programs to help families of these persons, in economical and social aspect;
- To reinforce and support services of psycho-social counselling for people living with HIV/AIDS and their family members. Counselling will help them not only to face problems they encounter, but important challenges will be resolved also, such as the reveal of status to the partners.