

The problems of care and rehabilitation for children with HIV: a cross-national study

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Abstract. *Over 41 thousand children have been born from HIV-positive parents in Russia since 2002. Due to modern medicine the transfer of HIV from parents to a child is managed to prevent in 98-99% cases, but in spite of this more than 2 thousand children, born from HIV-positive mothers have been still infected. The most recurring clinical implication of HIV among children is psychomotor and physical retardation. Another serious problem is biological and social desolateness, connected with HIV-positive status of their parents. Solution to many problems of social adaptation of HIV-positive children is possible in dispute.*

Key words – HIV, children, care, rehabilitation, health support, social support.

I. Introduction

Children with HIV get in orphanages or live for long in hospitals owing to death of one or both parents from AIDS, or because of being abandoned by HIV-positive mother, who finds herself in a distressed social-economical and psychological situation. About 20% children, born from HIV-positive mothers are in charge of the government. Because of social isolation Russian abandoned children at the age of 2,5-3 years lag 2 years behind their peers and have the development of 1-year-olds. Therefore, HIV is not just a disease. It is a complicated medical and social phenomenon, and if a medical aspect of the problem is now almost solved in Russia (HIV-positive children get full medical support owing to special social programs), the issue of social adaptation of such children is still open.

II. HIV/AIDS Strategy

6,800 HIV-positive people have been registered in the Kaliningrad region. This region was chronologically one of the first Russian regions involved in HIV-infection epidemic due to fast HIV prevalence among injecting drug users and gradual coming of HIV into general population through the heterosexual contacts. Our research team has had more than 12 years of experience working in the area of AIDS-prevention and rehabilitation of people living with HIV (PLHIV). Based on the results of the study there has been developed a study manual: "Ways to Use Physical Exercises During Medical and Social Support of PLHIV". This manual has been incorporated into the process of education on faculty of athletic department of the Immanuel Kant Baltic Federal University.

HIV-infected children are a special category of children that as a result of their disease face a number of social and psychological problems, such as intolerance, incorrect organization of communication of adults with children living with HIV, failure of the forms of such communication that prevail in childcare centers, and social isolation. These problems interfere with development of the body and spirit of HIV-infected children. Another serious problem is disclosure of HIV diagnosis to HIV-infected children [1]. Antiretroviral therapy has reduced mortality among HIV-infected children, and as they survive into adolescence, disclosing to them their diagnosis has emerged as a difficult issue, with many adolescents unaware of their diagnosis.

There is a need to build an empirical foundation for strategies to appropriately inform infected children of their diagnosis, particularly in Russia and Ukraine, which have the largest number of HIV-positive people in the Former Soviet Union Countries. Now social pedagogy is being in search of efficient means and facilities of such social adaptation. The United States of America is one of the countries with the largest number of HIV infections in the world. In addition, it is the first country that faced this problem and therefore the U.S.A. has considerable experience of HIV prevention and treatment. For a few years American scientists have been studying specifics of care and rehabilitation for children with HIV. These studies demonstrate that this is a complex problem and it demands a serious approach [2].

On July 13, 2010 the White House released the National HIV/AIDS Strategy (NHAS). This ambitious plan is a nation's first-ever comprehensive coordinated HIV/AIDS roadmap with clear and measurable targets to be achieved by 2015. The vision of the NHAS is: "The United States will become a place where new HIV infections are rare and when they do occur, every person, regardless of age, gender, race/ethnicity, sexual orientation, gender identity or socioeconomic circumstance, will have unfettered access to high quality, life-extending care, free from stigma and discrimination".

Unfortunately, in the Russian Federation there has not been conducted research on of social and pedagogical adaptation of HIV-infected children. In addition, Russian specialists are cut off from scientific experience of the U.S.A. American scientific articles, PhD dissertations and theses are not published in Russia. The only opportunity for Russian scientists to know about research studies of their American colleagues is to use the service of the U.S. National Library of Medicine and the National Institutes of Health (www.pubmed.gov). PubMed is a service of the U.S. National Library of Medicine that includes over 17 million citations from MEDLINE and other life science journals for biomedical articles back to the 1950s. PubMed includes links to full text articles and other related resources. It is possible to read here review articles about some studies on care and rehabilitation for children with HIV in the U.S.A.

III. Methods

Research scope: concept, model, organizational and methodical support of the psychological and pedagogical aspect of medical social support of HIV-infected children.

Research hypothesis: medical social support of HIV-infected children will be more effective if it is based on psychological and pedagogical methods targeted at preservation of health.

Research methods: psychological, sociological, pedagogical, medical, epidemiological, statistical.

Research tools: diagnostic tools (surveying and testing, functional tests, physical development assessment), dispensary cards of HIV-infected children, a PC with necessary software.

Expected results of the research:

- determine particularities of social composition of HIV-infected children, based on their sociometric and psychological status;

- give psychological and pedagogical characteristics of HIV-infected children; identify most typical groups for medical social support and education;

- develop the system of supporting and rehabilitation measures of psychological and pedagogical support of HIV-infected children;

- analyze the efficiency of supporting and rehabilitation measures of psychological and pedagogical support of HIV-infected children.

Planned scope of work:

1. Sociological studies of HIV-infected children (200 children in the FSU countries and in the U.S.A.).

2. Psychological and pedagogical testing of:

- HIV-infected children (200 children in the FSU countries and in the U.S.A.);

- specialists involved in medical social support of HIV-infected children (100 people in the FSU countries and in the U.S.A.);

- specialists involved in psychological and pedagogical support of HIV-infected children (100 people in the FSU countries and in the U.S.A.);

- family members of HIV-infected children (200 people in the FSU countries and in the U.S.A.).

The results of the research will help improve medical social support of HIV-infected children, determine their education strategy and future life orientation. The research data can be used by all specialists working in an area of HIV-prevention and fighting against AIDS, and also for preparing future specialists in pedagogy, therapeutic pedagogy, psychology, medicine and social studies all over the world. Moreover, the results can be very interesting for specialists from the former Soviet Union. Thus, the study will help conduct international research and will promote the increased standard of knowledge in the field of HIV/AIDS rehabilitation. The specialists of Imanuel Kant Baltic Federal University, Kaliningrad AIDS Centre and Saint-Petersburg Center for Control of AIDS and Infectious Diseases are already interested in these research results.

Results integration: development of guidelines for medical social support of HIV-infected children and interpretation of its results at the present stage; integration

of research results into medical care practices, psychology and pedagogy.

Research novelty: the system of organizational actions of psychological and pedagogical support of HIV-infected children adjusted for their condition will be developed, substantiated and tested.

Research stages:

2013 – 2014 – learn necessary research methods, publish research articles on the topic of the study, make presentations at conferences. There are many outstanding resources, exceptional clinical investigators and research programs in the U.S.A. that we will have access to and interactions with. These studies provide an excellent opportunity for us to observe and conduct a variety of different tests on HIV-infected children. We have attended U.S. HIV-clinical research group, where they discussed their and other ongoing projects, progress, challenges, and potential solutions. We have several didactic experiences in the U.S.A. for comprehensive seminars/courses on career planning, research skill building, selecting/working with a Mentor, study design-research protocol development, grant writing, grant/budget management, manuscript composition, grant/manuscript reviewer skills, biostatistics and biotechnology for clinical researchers. We have spent time with U.S. bioinformatics/biostatistical colleagues, so we have gained additional computer and software skills that they use to track participant testing, track data collection, and data entry, and set-up large databases for storing, sharing, and statistically analyzing clinical research data. These skills will be crucial to the planned cohort study of children living with HIV in the FSU countries. We also spent time designing the cohort study we planned to conduct in Kaliningrad, present this to U.S. research group, and set-up the data collection format and database for our prospective cohort study.

2014 - 2015 – carry out the research in Kaliningrad, Saint Petersburg and in the FSU countries, research articles on the topic of the dissertation, make presentations at conferences.

2016 - 2017 – analyze and process research data, develop methodological recommendations based on results of the research.

Conclusion

In case the experiment is successful, the received information will improve the quality of life of children living with HIV, not only in the Russian Federation, but also in the countries of the Former Soviet Union.

References

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