Human Immunodeficiency Virus (HIV) and persons with disability/intellectual disability: A review

Joav Merrick, MD, MMedSci, DMSc∗1,2,3,4, Ruth Talnir, MD2,5, Samuel Gross, MD, MPH6, Daniel Chemtob, MD, MPH, DEA7, Shoshanah Aspler, RN1,2, Isack Kandel, MA, PhD1 and Mohammed Morad, MD1,8,9
1National Institute of Child Health and Human Development, 2Office of the Medical Director, Division for Mental Retardation, Ministry of Social Affairs, Jerusalem, 3Zusman Child Development Center, Soroka University Medical Center, Beer-Sheva, Israel, 4Kentucky Children’s Hospital, University of Kentucky, Lexington, United States, 5Meuhedet Health Services, Even Yehuda, Israel, 6Hasharon District, Ministry of Health, Natanya, Israel, 7Department of Tuberculosis and AIDS, Public Health Services, Ministry of Health, Jerusalem, Israel, 8Department of Family Medicine, Faculty of Health Sciences, Ben Gurion University of the Negev, Beer-Sheva, Israel and 9Clalit Health Services, Beer-Sheva, Israel

Abstract

We have now known the Human Immunodeficiency Virus (HIV) since 1983, which has spread to all corners of our world. Somehow the population of persons with a disability has been neglected in research and outreach programs in spite of this population being at higher risk for exploitation and abuse. There are very few studies that have estimated prevalence in this population, but an international survey of 57 countries found that persons with a disability were at a significant risk of becoming infected with HIV in all the countries. This review looks at current information about the population with a disability and specifically intellectual disability. The population of persons with intellectual disability, both in community and residential facilities, is a sexually active population and there is a need for educational activities in order to prevent the occurrence of HIV infection or other disease transferred by sexual activity.

Keywords: AIDS, HIV, mental retardation, developmental disability, intellectual disability.

Introduction

Aquired Immuno Deficiency Syndrome (AIDS) was first identified in the United States in 1981 and has now spread to most parts of the world and all sectors of society. In 1983 French researchers at the Pasteur Institute were the first to isolate a previously unknown virus from patients with Aquired Immuno Deficiency Syndrome (AIDS). The virus that today is known as Human Immunodeficiency Virus or HIV is now readily identified through blood screening for HIV antibodies.

During the 1980s there was a rapid increase in the number of AIDS cases and deaths of people with AIDS in the United States and elsewhere and cases peaked with the 1993 expansion of the case definition and then declined with the most dramatic drops in both cases and deaths began in 1996 with the
widespread use of combination antiretroviral therapy (1). Since the year 2000 the annual numbers of AIDS diagnoses have been relatively constant, with an estimated 37,041 in 2006. In total, an estimated 1,051,875 people have been diagnosed with AIDS in America (1). People with AIDS are now surviving longer and this contribute to an increase in the number of people living with AIDS.

In Israel, the epidemiology of AIDS changed dramatically since 1991, when mass immigration from countries with generalized HIV epidemics arrived in Israel (2). The previous annual average of 60 new cases almost quadrupled with 68% among heterosexuals compared with only 11.6% before. In a study from 2004 (2) all HIV/AIDS cases in Israel ever documented aged over 13 years were studied and during 1980-2000, HIV and AIDS were diagnosed in 2,204 adults and 682 adolescents (cumulative HIV infection rate = 61/100,000). Of these, 65.2% are male (mean age 35.0 years old; SD = 11.0), 31.5% female (mean age 31.4 years old; SD = 10.5) (and 3.3%, sex unknown). The main modes of HIV transmission were heterosexual (45%), homosexual (16.9%) and drug users (11.5%).

**HIV/AIDS and disability**

For various reasons there is little information about HIV/AIDS and persons with disability (physical, sensory, mental and intellectual), but for example a study with data from the 1999 US National Health Interview Survey showed that adults with mental health disorders were more likely to report a medium or high chance of becoming infected with HIV, more likely to be tested for HIV infection and more likely to expect to be tested within the next 12 months than members of the general population (3).

There are very few studies that have estimated prevalence in this population and we have no prevalence data for any disabled populations from sub-Saharan Africa, Asia, Europe, Central and South America, or the Caribbean (4,5), but information from disability advocates worldwide point to significant unreported rates of infection, disease and death (4,5).

According to the World Health Organization (WHO) one in ten persons or about 600 million people have a disability (5), which was the reason for the World Bank to support a research project in 2003 at the Yale School of Public Health (5). This project was initiated in order to establish the current knowledge about HIV/AIDS and persons with a disability, to document current activities, identify good intervention models and identify gaps in the current systems (5).

Response to this survey came from 57 countries and it was found that persons with a disability were at a significant risk of becoming infected with HIV in all the countries. The following risk factors were identified:

- Poverty
- Lack of education
- Lack of information and resources to ensure safe sex
- Elevated risk for violence and rape and lack of legal protection
- Substance abuse
- Disabled AIDS orphans
- Lack of access and resources to pay for health care

It was also found that the lack of education and also impairment result in this population not obtaining or getting information about HIV/AIDS. That is one barrier, but it was also observed that people with a disability are not included in most HIV/AIDS outreach programs of prevention efforts. Two subgroups were found to even have higher risk for HIV/AIDS: women with a disability and ethnic and minority populations (5).

Southern Africa is the epicenter of the HIV/AIDS pandemic and a recent review (6) looked at the risk factors and again focus on the lack of knowledge and research in the disabled population.

**HIV/AIDS and intellectual disability**

One of the first cases of HIV infection in persons with mental retardation or developmental disability was reported by Kastner et al (7). This case report of two adults infected from homosexual activities showed that the care providers were unprepared for this occurrence and the two individuals, who became infected, experienced a deterioration in the quality of services. In the same period, the late 1980s, other case
reports were published identifying HIV in persons with mental retardation (8-10).

After the case reports published in 1989-91 (7-9) a study of 250 adults with mental retardation living in community residential facilities in New York (11) was conducted finding no cases of HIV infection. Another study was performed in a residential facility in Delaware with 345 participants with the same result (12). In a much larger study of seven California developmental centers (n=6,703) Lohiya (13) found 11 clients to be HIV positive (prevalence rate of 0.16 %).

A national American survey was conducted in 1987 (14) with responses from 44 states and a total of 45 individuals from 11 states were identified with HIV infection (31 in institutions and 14 in community settings). This survey was repeated in 1990 (15) with responses from only 13 states reporting on 93 persons with HIV infection (35 in institutions, 20 in community, 20 with place of residence not identified and six persons that had died of AIDS in the meantime). The means of transmission of the HIV infection was identified for 18 persons as heterosexual activity (three persons), homosexual activity (six persons), transfusion with contaminated blood or blood products (three persons), intravenous drug use (three persons) and one unknown. Both studies had several shortcomings due to the lack of response from states and a lack of monitoring of the situation in each state. In spite of that the researchers estimated that the true prevalence should have been between 250-500 adults with a further unknown number of cases in correctional and mental health facilities. Several researchers at that time predicted a future increase in the number of cases, which could be caused by the increasing number of children born with HIV-related encephalopathy due to maternal HIV infection (16,17).

The largest group of HIV-infected persons with intellectual disability (n=119) was found in a study by Walkup et al (18) using a database created by a match between the New Jersey HIV and AIDS Registry file through March 1996 and the New Jersey Medicaid eligibility file for the period of August 1993 to March 1996. Compared to the HIV-infected group without a mental retardation diagnosis the group with mental retardation was characterized as female, Black and having injection drug use as the source of infection. The level of intellectual disability was mostly mild or unspecified intellectual disability with only five cases diagnosed as severe intellectual disability.

A study from the United Kingdom (19) investigated the prevalence of men with intellectual disability who had sex with men in public places in three south east London boroughs. The work was administered through contact with providers of services for people with intellectual disability and identified 13 services where this was a management or practice issue, and 16 and 18 men for whom this behaviour definitely or possibly applied.

In 1998 we conducted a random sample survey in Israel of nine out of 53 residential care centers for persons with intellectual disability (total population 6,022) and found no case of HIV infection among the 1,321 persons tested (20). At present (2010) we know of three cases of HIV/AIDS in our residential care facilities and community related hostels and protected apartments (total population now about 10,000 persons).

Sexual behavior and prevention

In order to obtain information about sexual behavior and residential facilities for persons with intellectual disability a survey was send to 168 members listed in the Association of Public Developmental Disabilities Administrators 1998-1999 directory in the United States (21). Response rate was 68.5% and for the 46 facilities where 50% or fewer of clients had profound intellectual disability, sexual relations between clients was reported to occur "sometimes" or "often" by 29 (63%). Six of 115 (5.2%) administrators reported at least one client with a sexually transmitted disease in the past year. Of 110 instances of sexual abuse reported, the perpetrator was another client in 63% of cases. Ninety-six percent of administrators (n = 110) reported their facility had written guidelines concerning sexual abuse.

Some agencies have worked to prevent HIV/AIDS in people with disabilities using focus groups both with individuals from the target population, as well as service providers (22). Seven were persons with intellectual disability and nine services providers. Participants identified several contributing factors and barriers associated with risk behavior and HIV risk in this population. This study
again found that there is a need for development of specific HIV intervention strategies for this vulnerable and often overlooked population.

The population of persons with intellectual disability, both in community and residential facilities, is a sexually active population and there is a need for educational activities in order to prevent the occurrence of HIV infection or other disease transferred by sexual activity. The Division for Mental Retardation in Israel has therefore since 1991 conducted a one year education program (once a week with about 20 participants from various disciplines working in facilities for people with intellectual disability) in order to educate counselors to conduct sexual education programs for their clients. In general persons with a disability should always be included in prevention and outreach programs to prevent HIV/AIDS.

References


Submitted: January 01, 2010.
Revised: February 20, 2010.
Accepted: February 26, 2010.