Human immunodeficiency virus (HIV) in a residential care center for persons with intellectual disability in Israel: A needle in a haystack investigation

Samuel Gross, MD, MPH1, Joav Merrick, MD, MMedSci, DMSc2,3,4,5, Ruth Talnir, MD3,6, Shoshana Aspler, RN2,3, Isack Kandel, MA, PhD2, Mohammed Morad, MD2,7,8 and Daniel Chemtob, MD, MPH, DEA9

1Hasharon District, Ministry of Health, Natanya, Israel, 2National Institute of Child Health and Human Development, 3Office of the Medical Director, Division for Mental Retardation, Ministry of Social Affairs, Jerusalem, 4Zusman Child Development Center, Soroka University Medical Center, Beer-Sheva, Israel, 5Kentucky Children’s Hospital, University of Kentucky, Lexington, United States, 6Meuhedet Health Services, Even Yehuda, Israel, 7Department of Family Medicine, Faculty of Health Sciences, Ben Gurion University of the Negev, Beer-Sheva, Israel, 8Clalit Health Services, Beer-Sheva, Israel and 9Department of Tuberculosis and AIDS, Public Health Services, Ministry of Health, Jerusalem, Israel

Abstract

In Israel, the Office of the Medical Director (OMD) of the Division for Mental Retardation (DMR) at the Ministry of Social Affairs (MSA) provides medical services for persons with intellectual disability (ID) in residential care centers in Israel. The OMD sets the standard of care, and a medical/allied professional health team carries out inspections and supervision to staff at the local institutional level. This paper will discuss the first two cases of HIV/AIDS in a residential care center in Israel for children and adolescents with intellectual disability. The task force (OMD, Ministry of Health and police) established to investigate the two cases diagnosed with HIV/AIDS encountered several obstacles: 1) where should we look for a possible form of transmission? 2) as we suspected sexual abuse, where should we look and find “the needle in the haystack”? 3) parental opposition (the parents of the other children) to receive back the two cases to the center after they had started highly active antiretroviral therapy (HAART or cocktail) and 4) how to deal with a terrified staff at the center. We have learned several lessons from this case. First of all as physicians you also sometime have to play detective and in this case we were lucky that our investigation found the cause and the perpetrator. Second it is very important to have staff and parents informed along the way, even in very sensitive cases like this and to use all resources and collaborations available and create a task force as early as possible.

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

Introduction

Residential care is for people who are unable to continue living in their own home, even with support from family and care services. In residential care the stay can be for a short time (known as respite care), over a longer period or permanently. A residential care center/home provides accommodation, meals and
personal care. Personal care can include such things as assistance in getting up or going to bed, eating, washing, dressing and using the toilet by a staff available 24 hours a day.

There are many reasons for needing residential care, like if a person has significant physical disabilities, intellectual disability, mental ill health, an alcohol or drug dependency, or is at risk of injury or abuse. Residential care should provide:

- day to day support
- a comfortable and safe environment to live in
- activities of real interest and enjoyment
- privacy and dignity
- support for physical, spiritual, intellectual, emotional and social needs

In Israel, the Office of the Medical Director (OMD) of the Division for Mental Retardation (DMR) at the Ministry of Social Affairs (MSA) provides medical services for persons with intellectual disability (ID) in residential care centers in Israel. The OMD sets the standard of care, and a medical/allied professional health team carries out inspections and supervision to staff at the local institutional level. This situation is different from that in many other countries, where large institutions have been closed and supervision de-centralized. Israel has never had large institutions like those in the United States, but rather smaller centers having an average of about 100 persons per center. Only about 25% of the total registered population of persons with ID in Israel resides in this manner, whereas the majority remains at home, but receive services from the Division for Mental Retardation (1).

Residents in residential care are prone to infectious disease and because many people are gathered into the same space it is important to investigate every case in order to find the source of the infection and prevent others from getting the disease in question. Epidemiological investigation for the source of infectious disease is an important step in preventing the spread of contamination. This investigation is of primary importance in preventing the spread of any disease, but especially when we talk about HIV/AIDS, which until recently was considered incurable. Such an investigation is even more urgent, when this virus “breaks out” in a residential care center for children and adolescents with severe psychomotor disability, who can neither speak nor move on their own.

This paper will discuss the first two cases of HIV/AIDS in a residential care center in Israel for children and adolescents with intellectual disability.

**Case story**

The residential center in question is one of over 300 residential care centers, hostels and protected apartments under the auspices of the Ministry of Social Affairs and serviced by the Office of the Medical Director. This center is the home to 24 adolescents between the ages of 17-25 years, all with severe intellectual disability, associated medical problems, most without verbal communication abilities and wheelchair bound.

The case started in July 2008 when the supervisor from the Division for Mental Retardation (DMR) one afternoon informed the Office of the Medical Director (OMD) about a 24 year old female with severe intellectual disability (ID) hospitalized at a major medical center in central Israel, who had just been diagnosed with AIDS.

This 24 year old female with intellectual disability had been healthy until a year before the AIDS diagnosis. During that year she had suffered from chronic diarrhea and hospitalized three times at a local hospital for investigations of Crohn’s disease with colonoscopy and biopsy. After treatment with steroids was commenced she developed respiratory symptoms and hospitalized at a tertiary medical center, where her chest X-ray revealed pneumocystis pneumonia (PCP). This resulted in further investigations and positive HIV tests and a CD4 of 70.

The Office of the Medical Director together with the physician in charge of the Department of Internal Medicine and the epidemiology nurse of the hospital made an initial investigation for a possible mode of transmission and also notified the Ministry of Health (MOH). In the days afterwards the Ministry of Health and the OMD investigated the dental clinics, where the residents of the center were treated, as well as possible blood transfusions, inoculations and other
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possible ways of infections, but could not find a source for this infection and therefore also notified the police and requested a criminal investigation for sexual abuse.

Within a week the OMD called all the parents of the 24 children and adolescents for a meeting at the center and together with the MOH informed them about the situation and requested permission to test all children, parents and staff for HIV, which was performed a few days later with a quick test, which revealed case number two, a 17 year old wheel-chair bound male with intellectual disability, but generally healthy and a CD4 level of 338.

The task force (OMD, MOH and police) now encountered several obstacles: 1) where should we look for a possible form of transmission? 2) as we suspected sexual abuse, where should we look and find “the needle in the haystack”? 3) parental opposition (the parents of the other children) to receive back the two cases to the center after they had started highly active antiretroviral therapy (HAART or cocktail) and 4) how to deal with a terrified staff at the center.

Transmission

Here we were really looking for “the needle in the haystack”, but as the task force got more informed about the virus and the various types, groups and subtypes of the HIV virus, the OMD requested from the laboratory to subtype the blood from the two cases. The test revealed that we were talking about the same subtype for both cases and coming from an Ethiopian origin. With this knowledge the OMD requested from the director of the center to look back in the staff files 2-10 years (because of the low CD4 of the first case the infection must have been years back in time) and look for a profile of a male Ethiopian, who had worked on the same floor, where the two index cases were living.

A few days later the director informed the OMD that she had found a 37 year old male Ethiopian, who had worked at the center between the years 2002-2004 at the floor where the two index cases were living. He had been alone at nights on this floor and eventually fired, because of sexual harassment against another female staff member. The task force believed we had found “our man”, but before an arrest was made we asked the police to investigate if this person was know by the regional AIDS clinic. Here it was revealed that he was indeed known at the clinic a year earlier, when he, his wife and two newborn twins were diagnosed with AIDS after one of the twins died after delivery. In other words at the time of transmission to the two index cases he had not known he had HIV/AIDS. He was arrested and during the investigation admitted to sexual abuse of the female index case.

Parents

This case was difficult, because of the delicate nature of the case, a small facility where all parents are very involved and engaged in the care of their children and the emotions that erupted, when the case started and the parents were informed about the first case. The OMD has spent a lot of time trying to inform and keep the parents updated with several parents meetings over the past two years with collaborations from the MOH and also the Israel AIDS Task Force, a non-for-profit organization. The parents displayed strong opposition to receive the two index cases (the other parents only know the identity of the first case, because her parents accepted that all parents be informed) back in the facility after hospitalization and some of the parents (eight parents) petitioned the Court to block the return of case number one back to the center.

In a historic and lenghty court case the OMD and the MOH managed to convince the court that there was no medical reasons to isolate the index cases from the other residents or block them from their home in the residential care center.

Staff

This case was the first in a residential care center in Israel and staff was naturally worried and also shocked, so from the beginning the OMD spend time working closely with the director, to inform the staff and remain available whenever needed for questions or meetings with staff.
Discussion

Acquired immune deficiency syndrome or acquired immunodeficiency syndrome (AIDS) is a disease of the human immune system caused by the human immunodeficiency virus (HIV), which when a person is infected slowly reduce the value of the immune system and makes the person susceptible to opportunistic infections and tumors. The virus (HIV) is transmitted through direct contact of a mucous membrane or the bloodstream with a bodily fluid containing HIV, such as blood, semen, vaginal fluid, preseminal fluid or breast milk. This transmission can involve anal, vaginal or oral sex, blood transfusion, contaminated hypodermic needles, exchange between mother and baby during pregnancy, childbirth, breastfeeding or other exposure to one of the bodily fluids.

HIV infection is today considered a pandemic (2) with an estimated over 30 million people living with HIV worldwide and over 25 million people, who have died from the disease so far, both adults and children and especially in Africa the disease has resulted in many child orphanages.

Many people with HIV do not know they are infected, since most do not develop symptoms immediately after infection with HIV, while others have a flu-like illness within several days to weeks after exposure. They can complain of fever, headache, tiredness and enlarged lymph nodes in the neck and these symptoms usually disappear on their own within a few weeks. These symptoms can be like any other viral infection or flu and the person feels normal and can have an asymptomatic phase afterwards that often lasts for years. As the virus over time starts destroying our primary immune system (CD4 cells) the disease will progress (this state can last from a few months to more than 10 years) and the person in question is contagious and able to transmit the virus to others.

HIV infection will progress to AIDS when the body begins losing its ability to fight infections and the CD4 cell count falls low enough for disease to manifest (lower than 400). The infections are called opportunistic infections, because they infect a person, who is weak immunologically. The infections include (but are not limited to) pneumonia caused by pneumocystis (wheezing), brain infection with toxoplasmosis which can cause trouble thinking or symptoms that mimic a stroke, widespread infection with mycobacterium avium complex which can cause fever and weight loss, yeast infection of the esophagus which causes pain with swallowing and widespread diseases with certain fungi like histoplasmosis, which can cause fever, cough, anemia and other problems. HIV can have a profound affect on the gastrointestinal system and nutrition and cause symptoms ranging from poor appetite, rapid weight loss, diarrhea or profound fatigue.

Providing services to people in confined residential facilities will increase the likelihood for any infection to spread and especially when the facility is for persons without communication skills, immobile and with associated medical problems, as the case of residential care for persons with intellectual disability (3).

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. One study (4) was conducted to estimate the relative risk of sexually transmitted infections (STI) among children identified with learning disabilities through the special education system. This cross-sectional study used special education data and Medicaid data from Philadelphia, Pennsylvania, for the year 2002 with a sample of 51,234 Medicaid-eligible children, aged 12-17 years, 8,015 of whom were receiving special education services. The results showed that 3% of males and 5% of females were treated for an STI and females with intellectual disability were at the greatest risk (6.9%) and those in the emotionally disturbed or "no special education" category at lowest risk (4.9% each). Among males, STI were most prevalent among those classified as mentally gifted (6.7%) and lowest among those with intellectual disability (3.0%) (4).

The results from an earlier Israeli survey (5) in 1998 of a sample of 1,321 persons with intellectual disability in residential care indicated that at this point in time the population of persons with intellectual disability in residential care was free from HIV infection, even though the survey did not cover all 6,022 persons in residential care. At that time we had two cases (one male and one female) of suspected
HIV infection in persons living in community residential facilities, but both cases were not confirmed on re-testing. At the time of our last paper (5) we noted that HIV infection, both in the United States, but also in Israel, had not been able to penetrate into residential care to a large extent, but cautioned that with further normalization and community placements HIV infection would follow.

In the present paper we describe the first two cases of HIV/AIDS in residential care in Israel. The index case of a 24 year female with intellectual disability was the result of admitted sexual abuse by a staff member about 4-6 years before disclosure and the 17 year old male infected was either sexual abuse (even though the perpetrator did not admit) or hypothetically transmission between case one and two, but there is no epidemiological evidence for this hypothesis.

We have learned several lessons from this case. First of all as physicians you also sometime have to play detective and in this case we were lucky that our investigation found the cause and the perpetrator. Second it is very important to have staff and parents informed along the way, even in very sensitive cases like this and to use all resources and collaborations available and create a task force as early as possible. At the Ministry of Social Affairs level we are still debating how best to prevent cases of abuse and how we can survey and screen staff before and during employment, so that we can prevent cases like this. Our instructions for receiving new clients on admission have been clear and this way we have been able to know what we are bringing into the residential care system, but there is still a need to re-assess these guidelines and make sure they are following all the time.

Even though we can feel good about the low number of cases found in various studies (3-6) it most still be stressed that persons with a disability and especially intellectual disability are sexually active, prone to exploitation or abuse and therefore at risk for STI and also HIV infection. Sexual education and prevention programs are therefore needed for this population and the educational material must be adapted to the cognitive ability of the persons in question.

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References


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