Neurological and psychological complications of HIV

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This ATPA fact sheet looks at the various neurological and psychological illnesses that affect people with HIV/AIDS including AIDS dementia complex, toxoplasmosis, PML, lymphoma and depression.

The full text of the fact sheet is below. You can also download a printable PDF copy [1] of this resource, or contact us [2] to obtain hard copies.

Introduction

New treatment strategies for HIV have resulted in marked health improvements. Better treatment has also resulted in a renewed focus on the psychological health of HIV positive people. This facet of health is very commonly ignored but is increasingly recognised as crucial to the overall health of all people with HIV disease.

Psychological wellbeing impacts upon our general health, but specifically in HIV, ensures that treatment decisions are adequately considered, adherence to antiretroviral regimens is optimised and general quality of health is maximised. It's common for people in our modern, busy and complicated societies to experience some kinds of emotional or physical anxiety. For people with HIV, there is the added issue of a range of complications which may arise as a result of HIV infection, which may affect mental well-being, or directly affect neurological functioning (how the brain works). This may include increased susceptibility to depression or anxiety, or it may include a range of specific conditions or illnesses which can develop directly as an effect of HIV illness.

The purpose of this Fact Sheet is to untangle these issues and put them in perspective. While it is important to be aware of some of the key early warning signs of neurological problems, or of depression, it's important to remember that most people with HIV are not in imminent danger of developing dementia or any other HIV-related condition. And most importantly, there are things you can do to minimise this likelihood even more.

This booklet is divided into two sections. The first section looks at specific conditions or illnesses which may cause neurological symptoms or damage, and which can arise as a result of advancing HIV disease. It tells you what you need to know, signs to be aware of, and where relevant, how you can minimise your risks. The second part looks at the psychosocial effects of being HIV positive which may affect how you think or feel both emotionally or physically: things like depression or anxiety. It describes different ways of managing these problems should they arise for you.

PART A: NEUROLOGICAL COMPLICATIONS ARISING FROM HIV INFECTION OR OPPORTUNISTIC ILLNESS

AIDS Dementia Complex (ADC)

What is ADC?

ADC is an illness which results from damage caused by HIV replication in certain areas of the brain.

ADC is characterised by severe changes in four areas:

- cognition (your ability to understand, to process and remember information);
- behaviour;
- motor co-ordination; (your ability to co-ordinate muscles or movement);
- mood (emotions).

The likelihood of developing ADC increases with advancing HIV disease. This does not mean, however, that all people with advanced HIV disease will get dementia. Although ADC can occur at any CD4 count, it is uncommon in people with early disease and the severe form is usually seen only in people with very advanced HIV disease. Speak to your doctor about having a baseline [3]1. Information gathered at the beginning of a study from which

variations found in the study are measured. 2. A known value or quantity with which an unknown is compared when measured or assessed. 3. The initial time point in a clinical trial, just before a participant starts to receive the experimental treatment which is being tested. At this reference point, measurable values such as CD4 count are recorded. Safety and efficacy of a drug are often determined by monitoring changes from the baseline values. neurocognitive assessment which may be useful in allaying fears later on if you think you might be developing signs of dementia.

ADC is diagnosed by neurological assessment by an experienced clinician. The neurological exam is designed to reveal problems in short and long-term memory loss, problems with orientation, concentration, abstract thinking, or mood swings. Abnormalities of movement, gait (balance when walking) and reflexes can also be detected by physical examination. Many neurological complications of HIV can have initially quite similar symptoms, so it is important to rule out that these signs are caused by other problems, such as an infection which may require treatment. Brain scans may be used to help making the correct diagnosis. You should not assume or worry that any of the symptoms or signs described above mean you are 'losing your marbles'. Other things — including severe depression — might cause some of these symptoms. But you do need to tell your doctor if you have any of these signs, so that a correct diagnosis is made as soon as possible.

ADC is diagnosed after a lumbar puncture and a cerebral CT scan and a series of blood tests.

How is it treated?

ADC is treated by reducing HIV replication within the brain. In general the same drugs which reduce HIV replication in the blood also reduce HIV replication in the brain. If HIV is controlled in the blood stream it is generally controlled in the brain however some experts however some experts believe that ADC should be treated with anti-HIV drugs which are known to specifically penetrate into the brain tissue. AZT, which enters the brain tissue in high concentrations, is the most researched drug for treating ADC, but many other antiretroviral drugs also cross the blood brain barrier and may be equally useful in the treatment of ADC. Most patients respond well to this therapy and in many cases ADC can be reversed.

Sometimes other drugs are required to treat symptoms associated with ADC. These include psychoactive drugs, including anti-psychotics, anti-depressants, anxiolytics, psychostimulants, anti-manics and anti-convulsants.

Theoretically, the resumption of viral replication in the brain tissue of patients undertaking monitored treatment interruptions (MTI or drug holidays) may result in the acceleration of the development of ADC. Currently there is no evidence that this is a significant risk however it seems prudent that patients undergoing MTI should be monitored for early signs of ADC and recommence antiretroviral therapy should these occur.

|_. WHAT YOU CAN DO|

|* Talk to your doctor about HIV treatments, particularly if you have a rising viral load [4]A measurement of the quantity of HIV RNA in the blood. Viral load blood test results are expressed as the number of copies (of HIV) per milliliter of blood plasma. or falling CD4 counts

- Ask your doctor if they think you might be at risk of ADC. Consider baseline testing of your neurological status if you are.
- Talk to your doctor if you think you are experiencing any of the symptoms described above which might need investigation.|
  |_. WHAT YOU CAN EXPECT FROM YOUR DOCTOR|

  |* That they listen to your concerns.

- Referral to a specialist with experience in HIV neurology for tests if necessary.
- A clear discussion with you about your level of risk (which might very well be low!).
- It may be relevant to talk about changing treatments to ensure that HIV in your brain is being well-controlled.|

Neurosyphilis

What is neurosyphilis?

Syphilis is not a complication of HIV per se, but an increasingly common sexually transmissible infection which may be more difficult to manage if you are HIV positive. In particular, if it is not identified and treated, syphilis can cause neurological complications which can be extremely serious. This is called ‘neurosyphilis’. In recent years, cases of syphilis have been increasing, particularly in gay men. This is an infection caused by an organism called spirochete, Treponema Pallidum. Syphilis can progress to cause damage to almost any organ system, usually after remaining dormant in your body for a period of years. Neurosyphilis can cause failure of muscle co-ordination, dementia and staggering wide-based gait, postural instability, pain and abnormal neurological sensations such as numbness, tingling and burning. The development of neurosyphilis may be more common or accelerated in people with HIV disease.

|_. WHAT YOU CAN DO |

|* All people with HIV regardless of symptoms should have a baseline blood test for syphilis, and another three months later, to cover the window period for syphilis.

- You should have annual blood checks for syphilis if you are sexually active.
- Talk to your doctor or sexual health clinic to find out about protecting yourself from syphilis, and the signs or symptoms of this infection.|

Other Neurological Diseases

Besides ADC, people with HIV can be at risk of a broad range of neurological diseases and opportunistic infections, although most of these are now rare since the availability of effective antiretroviral therapy. However some positive people who are unaware of their HIV status and therefore have not had the chance to take effective antiretroviral therapy remain at risk for these conditions.

Progressive Multifocal Leukoencephalopathy (PML)

What is PML?

PML is a progressive sub-acute or chronic illness characterized by neurological findings such as paralysis affecting one side of the body, some loss of vision and changes in mental state and/or personality. PML occurs in up to 4% in patients with advanced HIV. It is caused by a virus [5]A small infective organism which is incapable of reproducing outside a host cell., JC virus. Before the era of effective antiretroviral therapy, PML resulted in progressive decline over the course of four to five months until death. Improvement or stabilization of symptoms for months to years is now common in people treated with effective antiretroviral therapy.

Primary Central Nervous System (CNS) Lymphoma

What is it?

Primary CNS lymphoma is a form of cancer which can cause lesions to develop in the brain. It is usually associated with advanced HIV infection, and like many HIV-associated illnesses and cancers, its incidence has rapidly declined due to improved treatments for HIV. People with this condition usually develop confusion, lethargy, personality changes and focal weakness e.g. paralysis of one side of the body. Diagnosis is usually made with brain scans although definitive diagnosis will require biopsy [6]Surgical removal of a piece of tissue from a living subject for microscopic examination to make a diagnosis (e.g., to determine whether abnormal cells such as cancer cells are present). or testing of spinal fluid for signs of cancer.

How is it treated?

Radiation therapy is used to treat CNS lymphoma. Anti-inflammatory drugs are sometimes used to help control symptoms.

Toxoplasmosis

What is it?

Toxoplasmosis is an infection caused by an organism called Toxoplasma gondii. Following exposure, the organism may cause a short feverish illness that lasts a few days. The organism then usually remains dormant in the body. As the immune system weakens with progressive HIV disease the organism reactivates and spreads to other parts of the body, usually the brain where it causes multiple abscesses.

Many people in Australia — HIV positive as well as HIV negative -have been exposed to the toxoplasma parasite, but illness in HIV is rare now that effective HIV treatments are available, to protect your immune system. An antibody blood test will tell if you have been exposed. Common sources of infection are undercooked meat (particularly pork and lamb), and cat faeces.

Initial exposure to toxoplasma can be prevented by making sure that any meat is cooked until it is no longer pink inside; wearing gloves while gardening or working with soil or sand; and wearing gloves and a mask when changing cat litter. If you have already been exposed you can avoid developing toxoplasmosis by commencing prophylaxis medication, (Bactrim), if your CD4 cells fall below 100 cells/mm3.

In the past, toxoplasmosis was the most common cause of mass lesions in the brain for people with advanced HIV. It is rarely seen nowadays because effective antiretroviral therapy preserves immune function and does not allow the organism to reactivate. Additionally, the antibiotic Bactrim, which is prescribed to treat or prevent the HIV-related pneumonia [7]An inflammation of the lung, usually caused by infection with bacteria or other microorganisms, in which the air sacs of the lung become filled with inflammatory cells which solidify and inhibit breathing. called pneumocystis carinii pneumonia, also protects against toxo. People with toxoplasmosis may present with:

- headache, confusion;
- personality changes;
- seizures, paralysis affecting one side of the body;
- other neurological deficits.

Diagnosis is made usually brain scans.

How is it treated?

Treatment is initially with an eight-week course of antibiotics called pyrimethamine and sulfadazine, followed by a lower maintenance dose, which is continued for life or until there is significant immune improvement due to HIV treatment.

|_. WHAT YOU CAN DO ABOUT THIS|

|* If you have a low CD4 count or AIDS, you may want to be tested for exposure to the toxo organism.

- If you have not been exposed before, it is important to avoid potential risks and sources such as undercooked meat. Wear gloves and wash your hands after working with garden soil, where toxo may live. If you have a cat, use gloves and a paper respiratory mask when changing its litter tray. Talk to your doctor about whether taking Bactrim to prevent toxo is appropriate for you. |
  |_. WHAT YOU CAN EXPECT FROM YOUR DOCTOR |

  |* Appropriate advice, discussion and referral

- Prompt attention to any symptoms you may report
- A discussion about prophylaxis if you have a low CD4 count|

Cryptococcal meningitis

Cryptococcal meningitis is caused by a fungal infection, which has become increasingly rare since the advent effective anti-HIV treatments. It is seen only in people with severely compromised immune systems. Headache and fever are the presenting symptoms but confusion, tremors and paralysis can also occur. A lumbar puncture is

required to make the diagnosis and monitor progress to treatment.

How is it treated?

Treatment is with a drug called amphotericin B, given intravenously, and flucytosine, followed by maintenance with oral fluconazole until the CD4 count is sustained above 100/mL.

PART B: PSYCHOLOGICAL AND PSYCHOSOCIAL COMPLICATIONS OF HIV

Depressed or just feeling sad?

There is a lot of talk about people with HIV experiencing depression much more frequently than in people without HIV. However, not all people with HIV will get depressed. In addition, there are things you can learn about depression which can help you understand this problem better.

Depression can be caused by a number of factors. Sometimes, these might be external factors, like death, loss, grief or life circumstances. Other times, it might be a depression caused by changes to your body chemistry which affects your mood: this is called ‘ clinical [8]Pertaining to or founded on observation and treatment of participants, as distinguished from theoretical or basic science. depression’. It is also important to recognise that many people go through periods of low mood, or feeling sad or blue, which may need to be distinguished from depression.

It is important to be clear about these differences, since not all depression needs to be treated with drug treatments, and it is important to be aware of
your options.

Living with HIV

When you receive a HIV diagnosis, it is understandable that you may experience a range of feelings as a result of the stress and uncertainty of the diagnosis, such as:

- Am I going to die?
- Will the treatments work?
- If they do, what about changes in body shape due to HIV and/or treatments?
- Fears of rejection, both realistic and unrealistic resulting in loneliness
- Feeling contaminated, and fears of contaminating others
- Not being able to work and resulting poverty
- Relationship breakup and resulting loneliness.
- Loss of sex drive

These thoughts are quite understandable, and do not necessarily mean that you have a clinical depression that needs to be treated by a psychiatrist and/or antidepressants. In the first instance, besides talking frankly to your doctor, your local HIV service or organisation for positive people will have a range of support services they can refer you to, such as:

- psychological counselling;
- peer support groups;
- social support;
- assistance with other issues like finances or housing.

Some of the things you can do to look after yourself and improve your emotional well-being may include lifestyle changes such as:

- talking to a doctor you trust, or to a supportive person such as a HIV treatments officer;
- looking after yourself: getting plenty of sleep, eating well and exercising;

taking some time out, such as a weekend away with friends;
recognising any symptoms or signs that your depression may be getting more serious.

More serious depression

Occasionally people develop more severe symptoms of depression that need to be diagnosed and medically treated. This kind of depression is caused by a change in certain chemicals in the brain, which fortunately in the vast majority of cases can be successfully treated with individual therapy, antidepressant drugs or a combination of both. Self-medication with herbal treatments for depression can be dangerous for people taking HIV antiretrovirals

Some of the signs of possible clinical depression can be some of the following that last longer than two weeks and are getting worse.

- feelings of sadness and/or irritability;
- crying a lot of the time;
- can't get out of bed or go out;
- loss of interest or pleasure in activities once enjoyed;
- changes in weight or appetite;
- changes in sleeping pattern;
- feeling guilty;
- inability to concentrate, remember things, or make decisions;
- fatigue or loss of energy;
- restlessness or decreased activity noticed by others;
- feeling hopeless, or worthless.

Again, it is important to make attempts to understand these symptoms. They may be symptoms of clinical depression, but they could also be signs of some other problems associated with HIV which need treatment. Depression is common, under-diagnosed and treatable across the whole of society, but depression rates are higher in people with HIV, especially those with advanced disease. This can have serious consequences not only in relation to your ability to adhere to antiretroviral therapy but also to make clear and informed decisions about your health. So if you experience a number of these things, you should see your GP.

Other things which can cause depression

Recreational Drug use

Recreational drug use may cause or exacerbate depression and anxiety. Many recreational drugs of themselves can cause depression, anxiety and psychosis, which can even, in extreme cases, lead to suicidal tendencies. These include alcohol; amphetamines (speed, crystal, ice); cocaine; ecstasy; and ketamine (Special K).

If you are taking antidepressants as well as extensively using recreational drugs, this will decrease your chances of getting better and can potentially lead to life-threatening interactions. There are growing concerns that excessive 'recreational drug use' can cause irreversible brain damage, intractable depression, and anxiety over the long term. If you think your recreational drug use is becoming a problem or harder to control, you need to have a frank discussion with your doctor or other health care provider. Talking to a trusted friend or a counsellor at your local HIV service can also be helpful. If these services aren't available at the time, telephone crisis lines such as the national Lifeline number 13 1114 is available to offer advice 24 hours a day in an emergency.

The role of HIV drugs in neurological and psychological side effects

Some antiretroviral agents can be associated with a range of neuropsychological side effects such as headache, anxiety, insomnia, abnormal dreaming and concentration difficulties. These effects are usually short-lived and resolve within a few weeks after starting the treatment. Sometimes, however, these problems persist. Some patients report ongoing fatigue, sleep and poor concentration, agitation and sometimes, a depressed mood which may last for months. Nevertheless, if the CNS effects do not wear off completely, or become intolerable, speak to your doctor. These effects may be experienced with any antiretroviral agent, but they are more commonly reported

with efavirenz (Stocrin). For more detailed information, see the ATPA Fact Sheet, Efavirenz, your doctor or the treatments officer at your local AIDS council.

- cryptococcal meningitis
- dementia
- PML
- toxoplasmosis
- Treataware
- Treataware fact sheets

Links:
[1] http://www.napwa.org.au/files/factsheet_hivneurology.pdf
[2] http://www.napwa.org.au/contact
[3] http://www.napwa.org.au/glossary/term/472
[4] http://www.napwa.org.au/glossary/term/416
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