Background
History and biology of HIV, Human Immunodeficiency Virus. AIDS (Acquired Immune Deficiency Syndrome) first identified as a condition in 1981 – collection of infections, tumours and other illnesses that can develop when HIV damages the immune system. HIV is a slow-replicating virus present in blood, semen, vaginal fluids and breast milk of infected people. HIV infects cells in immune system called helper T cells (CD4 cells) and decreasing levels of T cells leads to damaged immunity and vulnerability to a range of potentially life-threatening opportunistic infections. No real treatments until the mid-1990s and most people living with HIV died. Arrival of HAART (highly active anti-retroviral therapy) in the UK in 1996 transformed life for many but not all people with HIV. AIDS is no longer used as a term but rather HIV-related disease.

Currently around 100 000 people living with HIV in UK, approximately 20% unaware of infection. Annual HIV diagnoses increased rapidly until 2004 and then began to decrease, now heterosexual transmission and male-to-male transmission in the UK are at approximately the same rate. Globally, over 34 million people are living with HIV and each year, 2.5 million people become infected and around 1.7 million people with HIV die. The worst affected area is sub-Saharan Africa but spreading rapidly in Eastern Europe and Central Asia.

Terrence Higgins Trust West’s Services
Originally a local charity called Aled Richards Trust started as a Helpline in 1985, in memory of Aled Richards, one of the first people to die of HIV in the South West. ART grew with increased funding and need but merged with THT in 2000, mainly for financial reasons. Range of services including community support (buddying), complementary therapies, groups including Women’s Group, Strength for Action (BME) and social groups such as monthly BBQs, as well as range of health promotion including work with young people and men who have sex with men. Peer support is seen as crucially important for most people living with HIV. Counselling available short and longer-term from coordinator and small number of volunteer counsellors. HIV testing services at THT locally, as well as in the GUM/STI clinics – huge change in testing availability and process.

Major Developments
3 major changes have affected the work of HIV services and counselling, in particular, over the last 3 decades:

- Medications – range of HAART medications developed in early to mid-1990s and later significantly refined. Previously very complex regimes, now much simpler, e.g. couple of tablets a day but some have significant side-effects, some virus can become resistant to drugs, and adherence issues still remain for a variety of reasons (including self-harm).
Client Group – race/ethnicity; sexual orientation; ageing population. In 1987, vast majority of clients with HIV were white, gay men and now at THT West, roughly 40% of service-user group are women and 30% identify as African or African Caribbean, and a significant number are over 55 years old.

Social Issues – Stigma, discrimination and prejudice. Changed more in some communities but less so in others, with prejudice and harassment continuing for many.

Counselling Issues

Terminal to mainly chronic illness – learning to “live with” as opposed to “die from” HIV. From mainly illness, disability, disfigurement, end-of-life issues, bereavement and grief to the stresses of living with a chronic, mainly manageable condition. Still losses associated with HIV to be grieved – freedom, security, change in self-perception and identity. Many people will decide to use the counselling service at various points rather than continuously, as may have been the case more often in the early days when life expectancy was short.

Counselling at the time of diagnosis – may be shorter-term, including information-giving, immediate implications, choices and decisions (e.g. who to tell, including partner, family and work), circumstances of transmission (e.g. traumatic or potentially predictable) and of the test, degree of shock, self-blame and responsibility, systems, including family, friends and work.

Age and stage issues – some newly diagnosed in middle age and older now, some living with HIV for many years. Younger people newly diagnosed may not have developed coping skills useful for dealing with HIV. Growing older with HIV – longer-term side-effects of HAART (see later), general exhaustion, changing combinations, usual challenges of ageing, including existential issues, physical, social and financial challenges.

HIV diagnosis triggering previous traumas or partially negotiated life-stages or transitions – re-evoke painful feelings concerning gender, sexuality, ethnic identity, body image, sexual abuse. Connection between earlier trauma and vulnerability to infection. May involve inner child work, for example, or reparative/developmentally needed relationship.

Anxiety and depression – people with long-term physical conditions, including HIV, more at risk of developing mental health problems. Issues of power and control especially prevalent – e.g. concerning immigration status, money, medications and the future.

Medication-related issues - side effects of drugs can be debilitating (fatigue, digestive problems, liver and kidney damage, peripheral neuropathy, lipodystrophy). Complementary therapies, good diet and exercise can be helpful. Adherence to and changing medications. Control and self-harm through medications related to guilt, grief and stigma. Decisions to use medications or not. Suicidal ideation and behaviour.
• Immigration issues – asylum-seekers, rights to remain, racism. Cultural sensitivity, meaning of counselling within different cultures, sex and sexuality within cultural contexts, accessibility of counselling to members of different cultural groups.

• Poverty and benefits – changes to benefit entitlement; DLA reviews and PIP; impact of diagnosis on work.

• Existential Issues – meaning, direction and purpose, hopelessness and despair.

• Relationships and sex - “sero-discordant and concordant” relationships; disclosure issues generally; “reckless transmission”; sex and safer sex; pressure HIV places on relationships, 3 in the relationship, route of infection, impact of medications, ill health, social issues and challenges of longer-term relationships. Decisions to have children.

• Addictions – drug and alcohol issues, working in conjunction with other agencies; sex addiction, in person and on-line; life-style and self-care.

• Severe and enduring mental health problems – liaison with GP and mental health services, inter-disciplinary and inter-agency working; working with people on medications (anti-depressants and anti-psychotics).

• Cognitive functioning – HIV-related dementia; clinical psychology and cognitive functioning testing at Southmead Hospital; treatment routes.

• Treatment failure – people living with HIV can still become ill and die, from HIV and from other diseases. Impact of late diagnosis, virus becoming resistant to medications and severe drug side effects. Co-infection with Hepatitis C and/or tuberculosis. Support for family and friends. Children with HIV.

• HIV as liberating force still? – overall, the tasks of living with HIV have changed from coping with endings and death to managing continuing life and the future; from dealing with sudden, debilitating disease at a young age to coping with growing older with a chronic condition requiring life-long medications; from live-for-the-moment financial management to potentially struggling long-term on part-time wages, low benefits and a small pension. Some people still regard becoming infected with HIV as being a “wake-up call” to what is important in life.

• The Future? - “Treatment as prevention”; psychological support helping to prevent transmission through improved medication adherence and decrease in risk-related behaviour. Home testing and other “non-traditional” testing sites. Cure?

**Personal Approach to Counselling and Psychotherapy**

• Essentially humanistic in ways of being, informed by Rogerian core conditions.

• Trained in integrative counselling at Bristol University and Psychosynthesis Psychotherapy at Psychosynthesis and Education Trust, London.

• “HIV counselling” is really generic counselling with some specialisms and specialist knowledge, for example, sex and sexuality, internalised oppressions such as homophobia, racism, cross-cultural work, addictions, specific medical aspects of HIV and skills of multi-disciplinary working. Joint working with agencies such as Refugee...
Action and Age UK as well as internet support and services from myHIV.com and inter-disciplinary work generally important.

**Personal and Professional**

- Personal history, own therapy, role of supervision and continuing professional development, boundaries and different roles.

**Possible questions**

- What might be the major challenges for you when counselling people living with HIV?
- What additional training, if any, might you need when counselling people with HIV and how might your theoretical approach fit with the above issues and needs?
- Looking at the case scenarios below, what issues might arise for the clients and for you in your work together?

**Case Scenarios**

1. **Joe** is a 23-year-old, white, gay man who was diagnosed 6 months ago but who has only just come to THT for support. He doesn’t regard having HIV as a big problem due to the treatments available and yet is having difficulty sleeping and feels anxious leaving the house, especially when out with friends. He doesn’t want to meet other people with HIV and doesn’t really want to go to his initial hospital appointments. He continues to use recreational drugs such as ecstasy and ketamine at weekends, is using cocaine more often and has considered smoking crack. He says that he just wants to talk about future treatment options in counselling.

2. **Tatenda** is a 45-year-old, black Zimbabwean, heterosexual woman diagnosed 4 years ago. She works as a nurse in a local hospital and hasn’t told her employers that she has HIV but is fearful that they will find out. She attends THT’s Women’s Group despite being worried about confidentiality. Tatenda is concerned that her residency permit won’t be renewed and does not want to return to Zimbabwe, where many members of her extended family have died in the past of HIV. Tatenda is becoming increasingly depressed, not sleeping or eating well, and has recently stopped taking her HIV medications.

3. **James** is a 62-year-old gay man who has lived with HIV for over 25 years. He lost many of his close friends and his partner to HIV in the late 1980s and 1990s but continued to work for many years and had another long-term relationship of 15 years. James retired early on a small pension, partly due to the side effects of medications, and currently has no partner and only a couple of close friends. Once proud of his good looks in early adulthood, he now hates the sight of his body, his face is shrunken, legs skinny and veiny, and his belly swollen through years of medications. He longs for a younger boyfriend and more money and doesn’t think that counselling can help him, his consultant having recommended it for him.

4. **Jenny and David** are coming to counselling due to relationship problems. They have been together for 6 years and both are in their mid-30s. Jenny is HIV positive and was open about her status and the way in which she became infected when she met David. They now want to have children but David is finding being sexual with Jenny difficult and this is putting a strain on their relationship. Both Jenny’s and David’s
parents know about Jenny’s status but David’s mother has never been supportive of the relationship. Jenny worries that David will leave her for someone who is HIV negative and that she will lose the chance to have children. She has not used drugs for 8 years but is now feeling pulled back to using again.

Reading


Older articles related more to theoretical approach:


Pete Connor – 19/5/14

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