Psychological Issues in HIV

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HIV as a long term illness

- Advances in the treatment of HIV have increased life expectancy and quality of life for individuals and accordingly, psychological focus has shifted from coping with terminal illness to coping with a life long illness.

- There is a broad range of presentation with emotional distress - depression and anxiety, shame, with associated issues of poor adherence and poor coping with symptoms and or side effects of treatment.
A snapshot of the variety of presentations: heterogeneity

- An 18 year old female African student, social class 1, HIV due to rape, depressed.
- A 54 year old single heterosexual man with co-morbid alopecia, HIV acquired on holiday, socially anxious, avoidant.
- A 40 year old MSM with co-morbid social anxiety, HIV acquired by risky sex while depressed, now anxious and depressed.
- A 30 year old MSM with history of IVDU and other substance abuse, HIV acquired during addiction, socially isolated.
- A 32 year old terminally ill woman from vertically acquired HIV, non-adherent and depressed.
Variability, psychological adjustment and therapeutic approach

- Variability factors influence psychological adjustment and type of therapy offered:
  - Age at transmission, present age.
  - Gender
  - Pathway of infection
  - Cultural/Educational/Vocational background
  - Previous psychological adjustment / co-morbid psychiatric illness.
  - Co-morbid physical illness
  - HIV+ Symptomatic v Non symptomatic
  - Employment status
Age and adjustment

- Age at transmission and present age:
  - Most at risk group are young adults, however, due to success of HAART, there are increasing numbers of younger people growing up with HIV and older adults both becoming infected in mid life or surviving into old age with HIV.
Age and adjustment to HIV+ (2)

Perinatal infection with HIV

- 5000 in US in 2006 (Marhefka et al 2011)
- Small in depth study of 20 12 – 16 y.o. girls showed:
  - Gaps in transmission knowledge;
  - Perception of self as if “carrying a weapon” leading to abstinence or condom use
  - Disclosure as a shift in responsibility for transmission to the sexual partner.
Age and adjustment to HIV+ (3)

- Adults of 50 years and older will make up 50% of all HIV/AIDS in US by 2015.
- Review of literature (58 peer reviewed, data driven articles by Sankar et al 2011) showed:
  - Not homogenous: 3 main groupings: MSM, IDUs, Others.
  - Problem of distinguishing HIV symptoms from those of aging may delay diagnosis, as may stereotyping.
  - Stigma appears to diminish with age
  - Older adults less likely to disclose
  - Older adults engage in risk behaviours
  - Older adults adjust by using cultural and spiritual resources.
  - Adherence in older adults likely to be three times higher than in younger adults.
Employment status and QOL in HIV+

- In HIV-specific context in US, the prevalence of unemployment ranges from 45% - 62% (Bourgoyne 2001)
- Rueda et al 2011 explored the relationship between employment and physical and mental QoL.
- Found employment status highly beneficial to both physical and mental health even when disease variables controlled for.
HIV symptomatic vs non symptomatic (1)

- The psychosocial illness burden is highly variable but includes:
  - Fatigue
  - Oral thrush
  - Night sweats
  - Diarrhea
  - Persistent fever
  - Headaches
  - Weight loss
  - Skin rash/abnormalities
  - Cough/sore throat
  - Shortness of breath
HIV symptomatic vs nonsymptomatic (2)

- Neuro-cognitive function variability
  - Learning efficiency
  - Attention span.
  - Processing speed.
- Sensory neuropathy and pain.
Adjustment to HIV

- Adjustment is never a single or linear process (Brennan 2004)
- Task for people is to confront and manage the implications of illness, integrate events such as fluctuating symptoms, and make changes to their “mental maps” of their life narratives to that they can engage creatively with own lives.
- Adjustment is difficult to quantify, so our main focus is on patient acceptance and adherence.
Evidence based models to enhance acceptance of chronic disease: 1

- Common sense model of Leventhal et al (1980) has shown positive results with diverse chronic illnesses.
  - Principal focus is on person’s illness representations in four domains and how these affect coping style.
    - Identity: label assigned to the illness
    - Time line: course of illness
    - Cause of illness:
    - Consequences of illness
    - Cure: possibility of recovery or illness control.
CSM continued

- Identification and modification of beliefs especially in relation to Approval, Achievement and Comfort which mediate coping response
- Identification and modification of coping strategy from predominance of avoidant/passive/expressive to a more balanced active/planful/support seeking/responsible repertoire.
Evidence based models to enhance acceptance: CBT

- NICE meta review found good evidence for the efficacy of CBT with chronic pain and more limited but growing evidence for efficacy with a variety of physical illnesses.
- Main focus for acceptance in HIV+ is changing core beliefs and attitudes:
  - HIV as a punishment
  - HIV and shame
  - HIV and helplessness
  - HIV and unlovability
Evidence based models to promote adherence: CBT, Self Management,

- Adherence to ART is suboptimal in 20 – 40% of those in treatment depending on country.
- The key to improving adherence is the acquisition of behavioural strategies aimed at:
  - Attending appointments
  - Taking medication on time
  - Healthy lifestyle

Safren, Gonzalez and Saroudi (2008)
CBT, SM continued.

- There are specific programmes for adherence in HIV+ adults such as Life Steps (Safran et al 2008) which also acknowledge the significant impact of depression on adherence.
- Principals of self-management are also easily adaptable to HIV+ adults and also foster enhance self-efficacy.
Assessment for therapy:

- Symptom assessment, especially depression and anxiety.
- Patient level of acceptance/denial re HIV, and disclosure practice.
- Level of HIV+ symptoms (fatigue, gastric problems, sleep problems, medication side effects)
- Quality of life: exercise, diet, work and social engagement and support.
- Adherence level
- Explanation of CBT as a therapy of change and estimation of motivation (VAS)
Initial stages of therapy:

Despite differences in presentation, there is a commonality in experience: The diagnosis of HIV+ is a stressor which may elicit a variety of emotional responses including:

- Fear due to threat to survival
- Sadness in relation to losses
- Shame in relation to stigma

Patients require empathic understanding of their particular response to develop trust so that issues related to acceptance and adherence can be addressed (Sage 2008) and that goals can begin to be formulated.
Engaging client in change process:

- Motivational metaphors: e.g. *it's difficult to motivate yourself to do things differently if you are low, yet doing the same things digs you deeper into a hole. Doing the CBT is like giving up digging the comfortable hole and making a ladder out of the hole. It is tougher but it will help you live more fully with the HIV + and have a sense of well being and control.*
Flexible package of CBT modules:

○ Next phase is active collaboration with the person around their wishes which are converted into “smart” goals. Considerations include:
  ● What might be best to start with for patient/health?
  ● What really matters – to patient, for health?
  ● What might make a real difference?

○ Depending on presentation and goals a number of modules of CBT selected with focus on what the patient requires (Safran et al 2008)
Module on depression and HIV+ (1)

- Behaviour: avoidant, stays in.
- Physical sensations: fatigue, pain
- Emotions: depressed, sad, anxious, angry
- Thoughts:
  - “I will be rejected if people know I am HIV+”
  - “I’m too tired to go out”
  - “There is no point in trying”
  - “I will meet someone I know at the clinic”
  (after Padedsky and Moore 1990)
Module on Depression (2) – CBT strategies:

- Behavioural activation and scheduling pleasant events: gentle exercise and social engagement.
- Physical sensations: review pain control, relaxation training.
- Thoughts: restructuring of cognitions and awareness of mental traps e.g. catastrophisation, generalisation, mind reading etc.
- Emotions: label and separate emotions.
Module on Denial and HIV+

- Positive (constructive) avoidance
- Fearful avoidance
- Refusal to accept
- Public denial

- Use problem solving techniques
- Relaxations skills; Distraction, and cognitive work
- Increase awareness, by encouraging reflections and recall.
- Focus on cognitive work on shame.
Module on Denial and HIV+ (2)

- Positive Avoidance: aware of diagnosis but does not enquire or plan.
- Fearful Avoidance: becomes agitated or distressed if health issues are raised.
- Engage patient in reflection and graded planning for the future.
- Address anxiety with relaxation skills training, CBT for negative thoughts.
Module on Denial and HIV + (3)

- Refusal to accept minimizes symptoms, reluctant to be treated
- Public denial
- CBT for acceptance, shame
- Strategies for engagement, problem solving, CBT for shame.
Module on Adherence (1)

- Adherence includes attendance, taking medication on time, safe behaviour and healthy living.
- 15% - 36% of HIV+ patients may miss appointments and this is associated with increased risk for AIDS-defining illnesses and death. (Bofill et al 2011).
- Life steps in adherence training (Safran 2008)
  - Adherence Goals worksheet
  - Reasons (motivation) for adherence
  - Barriers and Planful coping strategies
  - Adherence Assessment Form
Module on Adherence (2):

- Education about adherence
- Plan for remembering and getting to appointments
- Plan for optimizing communication with treatment team
- Plan for coping with side-effects
- Daily schedule of medication with cues for times to take meds.
- Coping with slip ups.
Clinical example

- Patient not taking medication regularly as sleep is poor. This is impacting with loss of virologic control and disease progression.
- Patient experiencing vivid dreams, fatigue in the day, poor concentration.
- Assess sleep thoroughly with sleep diary: sleep pattern changes, getting to sleep, staying asleep, daytime naps.
- Assess for depression, substance abuse, lifestyle factors e.g. engagement in work, social support, activity levels.
Consider

- Interventions for depression, sleep hygiene, fatigue management, motivational interviewing for lifestyle change including work.
- Need for psychoactive medication.
- Change in type of HAART therapy

Saberi et al 2011
 Threats to one’s social self are accompanied by a specific set of psychological and physiological responses:

- Increases in shame
- Increases proinflammatory cytokine activity
- Increases in cortisol

(Dickerson & Gruenewald 2004 long term study)
Module on Shame (2)
Cognitive response to shame:

- Social evaluative threat – fearing or being negatively evaluated by others “They will think I am one of those gay guys that go to saunas”

- Perception of negative social evaluation are transformed into negative self-evaluation
  - “I am dirty, diseased, hopeless, careless, promiscuous”
Submission and withdrawal. These are adaptive in many primates as submissive display or withdrawal show that resources will not be contested or conflict escalated.

Sickness behaviour. Reduction in exploratory, sexual and social behaviour, immobility and reduction in food and water intake.
Module on shame: CBT interventions

- Behavioural activation and activity scheduling of positive events
- CBT cognitive restructuring for shame related cognitions:
  - Identifying cognitive distortions
  - Identifying negative automatic thoughts
  - Identifying dysfunctional attitudes/core beliefs.
  - Forming a more helpful or rational response.
  - Testing the thoughts in real life situations, working towards more accurate core beliefs.
Module on shame: Interventions

- Separate out internal shame from external shame (Gilbert)
- Moving from a “scared” position
  - Self-conscious
  - Conspicuous
  - Angry/anxious
  - Rejected
  - Embarrassed
  - “Different”
Module on shame: intervention

To Reaching Out (Coughlan & Clarke)

- Reassurance to others
- Effort, energy and enthusiasm generated to others
- Assertiveness
- Courage
- Humour
- Over there! Skill at focussing attention off the self to others/events etc
- Try Again
HIV+/AIDS Terminal care

- Despite progress, patients still may have significant illness burden, poor quality of life and illness progression.
- In the terminal phase, it may be appropriate to add to the range of intervention strategies a existential approach to assist the patient to come to terms with losses and impending death and to live as fully as possible until death.
Palliative Psychological intervention

- Focus is on quality of life, and what various choices mean to the patient.
- Whole person approach.
- Support to carers.
- Open, sensitive communication.
- Respect for patient’s autonomy and choice. (Lloyd Williams 2003)
Psychotherapy

- The capacity for psychological development continues throughout life, and when a person is diagnosed with a life threatening illness, it may have a profound effect, and a healthy push to integration and individuation may be stimulated.

- Just as plants throw off seeds when they are about to die, the life force can seem to intensify and many therapists have noted “the drive to truly live as death draws near” Schaverien (2002) Such patients may benefit from psychotherapy by experienced practitioners.
Positive consequences of long term illness.

- A number of small studies have shown some positive effects of long term illness (Sodergren & Hyland 2000, n = 100)
  - Improved interpersonal relationships due to increased empathy towards others
  - Reappraisal of life
  - Positive personality changes.
CBT manuals
