



HIV NURSING 2019



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HOSTED BY:



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Complexity in HIV Care

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Disclosures

I have undertaken paid advisory work and speaking invitations for:

ViiV, MSD, Gilead and Pfizer

It's just a pill once a day what the big deal?

- **“What's the problem? You take a pill once a day and that's it. So get off benefits, get back to work and lead a long and healthy life with HIV”**
- **“You just go in, get your bloods, the doctor says the numbers are OK, get the pills and get on with life”**
- **“Just call your doctor” “Just book an appointment”**
- **“At least you're alive!”**

The Modern Complex Patient

- **The presence of multiple, well-defined chronic illness with various complications**
- **Treatment with multiple medications**
- **Highly specialized treatment and highly effective invasive procedures both for diagnosis and treatment**
- **A peculiar combination of resiliency and fragility**
- **Unexpected responses to common medications and minor illnesses**
- **Longevity (living highly functional lives into the 80's and 90's)**

(<http://www.moderncomplexpatient.org/category/the-modern-complex-patient/>)

What Makes Complexity in HIV?

- **Multiple disease means multiple professionals with multiple appointments (Case management/Integrated Health)**
- **Potential poly-pharmacy and the drug interactions.**
- **Social issues – care packages, social worker input (adult & child), vulnerabilities, safe-guarding and protection issues.**
- **And....ageing, alcohol/drug use (recreational, street and chem sex), housing, finance, immigration status, language, literacy, capacity...**
- **Then add...stigma and discrimination, relationships, family dynamics, personalities, culture, history, experience, motivation!**

What Would I Say?

- **Physical complexity** – multiple diagnoses, co-morbidity, disability, issues of ageing, polypharmacy.
- **Psychosocial complexity** – drugs/alcohol use, language, culture, experience, confidentiality, stigma & discrimination
- **Socioeconomic complexity** – finances, benefits, housing, immigration
- **Professional complexity** – ‘it’s not our role/problem’...”oh they have HIV”
- **It’s everything!**

Complex or Complicated

- **We need to look at the complexities of health & social care not just how complicated it is to manage.**
- **Complex care needs skilled case management which requires a multidisciplinary team approach from the HIV team, GP, social services, palliative care, district nurse, support worker, drug/alcohol worker, psychologists, psychiatry, etc, etc, etc.**

Who's who?

- Partner, friends, family
- GP, practice nurse, district nurse
- Other specialist consultants – ageing, renal, cardiac...
- Psychiatrist, psychologist, psych. nurses, drug & alcohol workers, crisis team, support workers.
- Social worker (child & adult), carer's, housing workers, advice agencies
- HIV Voluntary services, respite care, palliative care, peer support.

Case Study - Sam

- Sam, 83, gay man, widowed (19 years)
- HIV positive for 25 years, controlled on TAF/NVP
- Ischaemic heart disease, dyslipidaemia, renal impairment, mild haemophilia, hypertension
- Admitted to hospital after falling in the street
- Referred for 'support around ARV's and concerns re. memory and complexity.
- Would he be classified as complex?

UK Payment by Results

- **Complexities (as devised in 2009) are listed as:**
 - Current TB co-infection on anti-tuberculosis treatment
 - On treatment for chronic viral liver disease
 - Receiving oncological treatment
 - Active AIDS diagnosis requiring active management in addition to ARV (not inpatient care)
 - HIV-related advanced end-organ disease
 - Persistent viraemia on treatment (> 6 months on ARV)
 - Mental Illness under active consultant psychiatric care
 - HIV during current pregnancy

UK Payment by Results

- The nature of HIV disease means that patients may have an additional range of complex psycho social needs, which go beyond the remit of the hospital, based HIV team to meet. The cost of meeting such needs is not included in the tariff development to date.
- However, in developing the HIV Currency it is acknowledged that there are a number of patients with complex psycho-social needs who may inappropriately rely on the HIV clinic to meet those needs
- One of the fields in the data set allows both providers and commissioners to monitor the impact of patients being under the care of social workers.

Sam on Assessment

- **Lives alone (with his cat) 5th floor, no lift**
- **States he is lonely and isolated, all other property in his building are offices, closed at weekends/holidays**
- **Fall 2 months ago, feels dizzy all the time**
- **Care package (2 x 2 hours a week –cleaning/shopping)**
- **Lives on sandwiches – doesn't cook (too time consuming)**
- **Numerous hospital appointments needing transport**
- **Discharged from hospital – asked to leave by security after the ward lost his wallet, discharged home with no money/food on a Thursday evening**
- **Agreed to visit weekly!**

Sam weekly visits

- **Stopped ART – weeks ago “do you know the side-effects are dizziness”**
- **In pain, won’t take paracetamol “it can kill you”.**
- **Attended hospital three times in one week, out of the house 6 hours each day, fed up and angry**
- **Has volunteer visitors 5 days a week, feels he needs more “they are always on holiday”, “she’s leaving London” seems to be very angry about it.**
- **Good relationship with GP – home visit last week stopped medications (can’t remember which)**

What are the issues?

Recurrent falls have kept him a 'prisoner in his home'.

Hyperchondriac – watches TV thinks he's ill, highly anxious, reading side-effects. Numerous appointments in 3 hospitals.

HIV – controlled by TAF/NVP

Care is sporadic – different people, different times. Relies on volunteers who may or may not visit. Very angry about lost friendships

Poor self care – eats poorly, last saw a dietician in 2000.

Sam – Further Visits

- **10 calls to speak to his GP – took 2 weeks to respond**
- **Called Social Worker to clarify care package (he's been discharged). Called care agency to request continuity and timings. Carers encouraged to buy meals not sandwiches**
- **Confirmed medications with GP and HIV clinic, consolidated hospital appointments (HIV and falls clinic)**
- **Discussed issues with volunteers and rationalized visits**
- **Saw a TV programme about super gonorrhea – wants to know how he can be checked!**

Sam Further Visits (2)

- **Flood in flat caused by leaking roof**
- **Cinnamon trust now visiting his cat (and him) 5 days a week**
- **Feels his foreskin is too tight, doesn't want a circumcision but now anxious he'll need one.**

What's the Healthcare Professional's Problem?

- 1. Referral – what we're told versus what the patient thinks.**
- 2. Communication -**
 - Electronic notes on different systems**
 - No easy telephone access with anyone.**
 - No emails, fax only.**
- 3. Interpretation on the case – one person's manic is another person's eccentricity.**
- 4. Happy to let others do the work – who is best place to lead...most involvement, pressing need, longest involvement.**

Capacity

- In English Law, an adult has the right to make decisions affecting his or her own life, whether the reasons for that choice are rational, irrational, unknown or even non-existent. This right remains even if the outcome of the decision might be detrimental to the individual
- However, such a right to self-determination is meaningful only if the individual is appropriately informed, has the ability (capacity) to make the decision and is free to decide without coercion (Grisso, 1986).
 - Grisso, T. (1986) Evaluating Competencies: Forensic Assessments and Instruments. New York: Plenum.

What Can I Do?

- **Prioritise – compare your ‘vs’ your patients top 10 problems – is there a match?**
- **Work with the patient – it’s easier than you think, if they can make them take the lead.**
- **Offer to lead the care if no one else is willing to (or fight to lead it if you feel you know the patient best)**
- **Do what ‘you’ need to do and ensure others know their roles and stick to them.**
- **Consolidate & rationalize!**
- **Communication – find a way around it, safe emails, direct lines, mobile numbers, text, fax...whatever works easiest & best.**

Who Leads Care?



Who Really Leads the Case?

