

HIV NURSING

CARING FOR PEOPLE AFFECTED BY HIV

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HIV NURSING

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Aims and Scope

HIV Nursing has been developed as a forum for those at the forefront of caring for people affected by HIV. The journal is supported by a highly respected Editorial Board drawn from a wide range of nursing specialties. This is further strengthened by an Advisory Panel who will be making regular contributions to the journal.

HIV Nursing is intended to provide a medium for communication on issues relating to HIV care, which will be run by the care professionals for those involved in the day-to-day matters affecting the lives of patients.

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User involvement: empathy, voice and partnership

Nathaniel Ault

HIV Consultant Nurse, Barts Health NHS Trust

Welcome to the autumn edition of *HIV Nursing*, in which we look at 'Relationships and responses' – how patients and clinicians interact, the outcomes that shape everyone's behaviour and understanding ... and the resulting improvements in how we work together.

Features include an account of a previous needlestick injury sustained by Janice Rees while on a home visit. Her initial response was to keep it to herself to avoid causing worry to her family – and, notably, her patient who she felt would be 'mortified' and would hold himself responsible. She did ultimately tell her family and she shares with us her diary of post-exposure prophylaxis (PEP). Janice has also identified a distinct lack of research on the psychosocial effects of taking PEP, which she found to be in parts a difficult experience despite a supportive family.

In the area of midwifery, Judith Sunderland shares her personal perspective on methods for teaching student midwives about HIV and pregnancy and offers suggestions for improving communication and awareness among the various individuals and teams involved in the journey of those women who are diagnosed positive antenatally. The ultimate aim is, of course, improved care for mothers and their babies in both the short and the long term.

We are very pleased to include in this issue the 2012 Conference abstracts, an impressive total of 50 for this year. The current issue theme is well represented in this year's abstracts, which fall broadly into the following categories:

- Specific approaches/care models/audits and surveys: 34% (17)
- Patients' views, behaviour and responses: 22% (11)
- Nurses' roles in various contexts: 12% (6)

- Management of follow-up, referrals and transition: 10% (5)
- Patient support: 6% (3)
- Patient participation: 4% (2)
- Approaches for specific groups: 6% (3)
- Public perceptions: 4% (2)
- Policy shaping: 2% (1)

As well as NHIVNA and BHIVA members, abstracts were contributed by NHIVNA trustees past and present, previously published authors in *HIV Nursing* and representatives from NAT and Body and Soul. With a wide range of themes and content, there were plenty of fresh perspectives and new material for us all to mull over. Thanks to all those who contributed and helped make conference a spectacular success – with congratulations to the worthy award-winners (details available on the NHIVNA website).

Last but not least is a contribution from Juliet Bennett on how clinician–patient relationships have evolved and what is the current state of play. The doctor as dictator is far behind us, and today we see the marketplace construct firmly in place where the patient as client is theoretically able to voice their needs through self-management and patient empowerment, thus facilitating more effective care.

As the population lives longer, this is a logical development in many ways. However, social inequality is amplified in this context, as in state schooling, with the better educated and more articulate service-users reaping the greatest benefits from what the state provides. Other thorny issues include conflicts between patient and clinician, cost implications, and the question of where a clinician should 'draw the line' in terms of accommodating patient input. My own perspective on user involvement is below.

Case study: PEP decisions and outcome

Introduction and background

Mary, a PEP patient, completed her 28-day course of PEP as a result of shared decision-making, despite a shaky start. Once initial problems with fatigue and side effects were resolved, she managed to complete on an alternative regimen which worked better for her.

In 1992 Roter and Hall described four basic forms of 'doctor-patient relationship [1]', though in today's context of HIV care and advanced practice nursing, this would more accurately be termed, 'clinician-patient relationship'. These are:

- Default relationship: neither clinician nor patient has control. The potential lack of goal

Continued over

Table 1: Significant stages in shared decision-making

1. Does the patient understand enough for informed choice?	I spent time with Mary looking at the risks and at how we consider and calculate risk in relation to PEP-prescribing decisions. We reviewed the circumstances under which guidelines may move from a 'Consider' to a 'Recommend'. We also discussed Mary's thoughts about risk and whether a 'lack of signs and symptoms of HIV' in the source was really an indicator of infection, along with the source's history and what might have occurred since her last encounter 18 months ago.
2. What are the options for the patient?	Mary's choices were wider than continuing as she was or just stopping altogether. The BHIVA guidelines [5] allow change of PEP if it is not being tolerated for side effect reasons. The options given are atazanavir/ritonavir or darunavir/ritonavir as the protease inhibitor if changing from lopinavir/ritonavir. I felt that lopinavir/ritonavir was likely to be the cause of the increased fatigue, and certainly this is supported by the British National Formulary [6] (2010), while the Summary of Product Characteristics also lists this as a common side effect. Interestingly, the same property is noted for darunavir and atazanavir, but my clinical experience has found this less common with once-daily dosage. Thus the options became: <ul style="list-style-type: none"> ▪ Switch to atazanavir/ritonavir ▪ Switch to darunavir/ritonavir ▪ Continue with lopinavir/ritonavir ▪ Stop PEP
3. What are the pros and cons of each option?	We carefully explored common side effects of the three regimens. Mary was concerned regarding the rise in bilirubin and its possibly noticeable consequences – and of course did not want to continue lopinavir as she was already having difficulty with this. She was apprehensive about continuing PEP given her experience so far, so we came to an agreement to try darunavir/ritonavir for one more week and then review her PEP. We agreed that Mary could then stop at this point – but given our discussions on, risk she felt the change was worth a try.

The patient then makes informed decisions for the following three options:

- (1) Do I want to stay on the same treatment? (2) Do I want to change treatment? (3) Do I want to stop treatment?

Continued

identification and achievement here does not benefit the patient's care in any capacity.

- Paternalistic relationship: dominant clinician in contrast to passive patient
- Consumerist relationship: the focus on patients' rights and clinicians' obligations gives far more power to the patient.
- Mutualistic relationship: centred on shared decision-making, with equal power, and often seen as the best type of relationship. Michelle Croston's presentation at Conference in June, about how we listen, or don't listen, to patients in consultations is relevant here.

An alternative approach [2] proposed that a clinician-patient encounter can be defined by how much the agenda is set by the patient, the clinician, or both. Whichever way you choose to assess this, shared decision-making is clearly the way that all healthcare, including HIV care, is and has been evolving. Whilst Juliet Bennett has eloquently explored this change from a theoretical viewpoint, the aim of this case study is to take a clinical perspective. Therefore let us explore the story of Mary.

Presenting complaint and history

Mary, a 35-year-old African female, attended for follow-up in one of my PEP clinics, having been started on PEP. She felt she could not tolerate it and wanted to stop. Having been forced into non-consensual sex with her ex-partner over the previous weekend, she had been seen in a London sexual health centre and referred on to one of the London Havens for assessment and forensic screening. Her ex was a black African from a high-prevalence area and they had not had sex for 18 months. The 'word on the street' was that he had a history of forced sexual encounters and she had also learnt recently that he had told lies throughout their relationship. Further history-taking revealed that Mary had been diagnosed with chlamydia and possible pelvic inflammatory disease (PID), and had been on a course of antibiotics at the time of the forced sexual assault.

Mary was complaining that since starting PEP she had been feeling generally unwell, with 'underlying' nausea and 'total exhaustion'. She constantly felt the need to sleep and could not concentrate in her demanding job at an advertising agency. She just wanted to stop the PEP. During the

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consultation, she offered many reasons why her ex-partner would be negative – including her own negative result 4 months previously. No significant story of drug use or allergy emerged, nor any relevant medical, family or social history. Baseline bloods at commencement of PEP were all normal, except for a slightly raised bilirubin at 22, for which no reason was apparent.

Decision-making positions

The patient's agenda

Mary's agenda was to stop the PEP. She was not tolerating it well and it diminished her performance at work, which was very important to her.

The clinician's agenda:

Given her presenting history, I judged that we would recommend PEP for the full 28 days. BASHH guidelines [3] suggest that vaginal intercourse with a male of unknown HIV status would fall into the 'Consider' category. However, Mary was being treated for a sexual infection; this was a forced sexual encounter; and we knew only that the male was from a high-prevalence background and may have had unprotected forced sexual intercourse with other females in the 18 months since the relationship broke up. I therefore felt that this moved the exposure into the 'Recommend' category. Clearly, patient and clinician are here coming from two markedly discordant positions.

Developing a shared process

In shared decision-making, it is important that the patient is empowered to make a decision based on the best information available. How this is explained is also very important. I could have taken a paternalistic approach that would end with the patient being 'told' or 'strongly advised' in an authoritative manner 'to continue' – but this would not be shared decision-making. Shared decision-

making can be seen as evidence-based patient choice [4], that is, presenting the evidence and choices to the patient in a neutral manner and allowing the patient to make a decision based upon that evidence. My own approach to shared decision-making, and how this was applied for Mary, is outlined in Table 1.

Outcome and conclusion

Mary returned to the PEP clinic a week later feeling much happier with the new medications. Her nausea had stopped and her fatigue 'virtually gone', allowing her to function much better in her work environment. The work done with Mary to help her achieve shared decision-making led her to become much more involved in the process of her PEP management. She was motivated to consider options beyond the limited choice she initially felt she had and was able to complete the 28 days of PEP with no further issues. She will shortly be due for her 3-month follow-up testing.

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The journal's Editorial Board will be holding a meeting in **October** to discuss themes for next year's issues — so please send in your theme suggestions and any contributions or queries to:

naomi@mediscript.ltd.uk

We need to receive any content-related emails by 28 September 2012.

Thank you.



HIV post-exposure prophylaxis – a brief review

Janice Rees

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After a needlestick injury some years ago, my decision to take PEP and what happened is recorded in the diary that follows. I wanted to find out more – but it soon became clear that little data is available.

Introduction

Occupational exposure to human immunodeficiency virus (HIV) in a healthcare setting presents a low but potential risk of infection [1]. Animal models show that after initial exposure, HIV replicates within the dendrite cells of the skin and mucosa before spreading through lymphatic vessels and developing into a systemic infection [2]. This delay in systemic spread leaves a 'window of opportunity' for post-exposure prophylaxis (PEP) [2].

No large prospective randomised controlled studies have been performed to determine the efficacy of occupational PEP, and the ethical issues involved in conducting such trials make it unlikely that they will occur in the future [3]. The evidence for the prescribing of PEP derives from work undertaken by the Centers for Disease Control in America. This retrospective study of healthcare workers who had occupational exposure to HIV showed an 81% reduction in seroconversion in those who took azidothymidine (azidothymidine/zidovudine) for 28 days following exposure [3].

Many countries now recommend PEP following occupational exposure to HIV. UK guidance is issued by the Department of Health, and the recommendation is for staff to be offered a combination of two antiretroviral drugs – Truvada (tenofovir/emtricitabine) and Kaletra (lopinavir/ritonavir) – which need to be taken for 28 days [4].

The research

There is a plethora of information relating to the physical side effects that staff who take PEP may experience. Common among these are gastrointestinal disturbances, headache, myalgia, arthralgia, fatigue and blood disorders [5]. Staff should be informed of these side effects before taking the medication, and symptom control is often possible through the use of medications such as anti-emetics.

The extracts from my diary highlight that even the most informed person can be psychologically affected by taking PEP. I was very surprised at my reaction. I have always seen myself as very level-

headed and logical – but at times whilst on the treatment, particularly in the first few days, I was an emotional wreck! I wanted to find out if this is a common experience amongst healthcare workers but there is very little research documenting the psychological effects of taking PEP.

Two healthcare workers in America were diagnosed with post-traumatic stress disorder (PTSD) after being prescribed PEP [6]. Both received a 4-week course of PEP and underwent the recommended medical evaluation and counselling. Neither worker had a history of psychological problems prior to the injuries. Both suffered from persistent depression, anxiety, insomnia and recurring nightmares. Both had panic attacks when they attempted to return to work 2 years after the injuries and when they had tested negative for HIV. Another case report documents a healthcare worker with a previous history of major depression. He was diagnosed with PTSD following a needlestick injury from a known HIV-positive patient [7].

A retrospective study undertaken in 1990 interviewed healthcare workers at an average of 19.5 months after their exposure to HIV-infected blood. Acute distress was reported by 55% of them and moderate distress by 35% – while 30% quit their jobs [8].

While the reaction and support of my family was very important to me, I could not find any papers relating to the effect on a healthcare worker's family when their loved one has sustained a high-risk injury or been prescribed PEP. Similarly, I could not find any articles relating to the source patient involved in such an injury. I chose not to tell the patient from whom I sustained the injury because I was aware of his BBV status and was concerned that he would be mortified and worry that I might have contracted the virus from him.

Conclusion

There is clearly a void in research relating to the psychosocial effects of taking PEP. It has been suggested that the emotional effects of occupational exposure to HIV may be under-appreciated and

hence inadequately studied. Guidelines for the management of nosocomial (hospital-associated) exposure to HIV do not discuss the possibility of psychological disorders after such exposure [6].

This issue should be addressed by both occupational health departments and physicians who prescribe PEP. This is also relevant to those prescribed PEP for non-occupational reasons such as sexual exposure. Support, counselling and follow-up for at least a year should be a routine part of the care of anyone prescribed PEP [6].

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A diary of PEP

Janice Rees

The day it happened: Wednesday

I consider myself to be a logical person; I can weigh up risks and make decisions. Yesterday, I went to the home of a HIV positive patient who I will call Alan. Alan was diagnosed a while back and had been on medication since diagnosis. He was a compliant patient who had had an undetectable viral load for a couple of years. This has been a very cold January and, because Alan can't afford to keep his house as warm as he'd like, he keeps warm in the day by covering himself with a duvet. I took blood from Alan and, as I removed the needle from his arm, I said, 'there we go – all done'. At this point, he shivered – it was a particularly cold morning. So, as I was placing cotton wool over the puncture area, I punctured my left index finger just below the nail. As it happened, I thought 'Oh! Ok, no problem, Alan has an undetectable viral load.' I didn't let on to him what had happened because he would have been mortified and blamed himself and worried. He is the epitome of the gracious gentleman. I encouraged bleeding of the puncture wound as I was sorting out his samples so that he couldn't see.

I then drove back to the hospital – a 20-minute drive. As I was driving I was thinking logically: the risk from a needlestick injury is incredibly low – 99.7% of people who receive injuries from known HIV-positive patients do not become infected. Alan had an undetectable load so the chance was negligible. Should I take PEP? I decided emphatically, no! How stupid would I look and feel? I knew the risk was low, it was negligible – how could I support staff if I took it when the risk wasn't there? Occasionally a little red devil on my shoulder would pop up and say, 'but what if you were the unlucky one – what would your family think? You had the chance to save yourself and you didn't!' I easily knocked him off and logic would again take over. At one point I considered not even reporting the incident because the risk was so low.

'I saw my children and all sorts of images ran through my mind.'

I got back to my office and immediately told a colleague what had happened and she was very supportive. With hindsight, if it had been a day when neither of my two colleagues was in, I don't honestly know if I would have reported what had happened. I phoned the regional HIV centre and asked to speak to the consultant I work with as I wanted an unbiased view and he is someone whose professional opinion I trust completely. He was in Cardiff in a meeting so I spoke to another member of staff who supported me in the way I would support any member of staff – 'the risk is low, there are nasty side effects, but ultimately the decision is up to you'. This is exactly what I would say to staff – and I would be thinking as I spoke to them, 'don't panic, don't worry – you'll be fine'. I reported the incident in the routine way – had baseline bloods taken for storage and decided not to take PEP. My day carried on as normal. Occupational health staff were very supportive but as all had been done and I didn't want PEP, I just got on with my work.

Then I got home ...

I saw my children and all sorts of images ran through my mind. How would they feel if they knew this had happened and I had done nothing to try and prevent myself becoming infected? They have always known I deal with infections and, as they have got older, have understood that I deal with people living with HIV – something they have been very chilled about. In the past they have asked me if could I get it, and I have always told them the truth: 'No, not by looking after people, but there is a tiny, tiny chance that if I pricked myself with a needle, I could – but the doctors would give me drugs to stop this happening.'

'The stats show a negligible chance of becoming infected. But what if I was that 1?'

I got on with making supper, and then my husband came home. As usual he said, 'Good day?'. I said 'No' and told him what had happened. He said, 'You're not worried, though, are you?' and my answer was, 'No, the patient had an undetectable viral load – the risk just isn't there and so I didn't take the medication.' Then we carried on as normal, having supper, sorting out household stuff and nagging the boys to do their homework! But all the time I had this silly niggle going on. A totally irrational niggle but it kept digging away at me. I found myself snapping at the boys and my husband (more than usual!) – it was constantly there.

That night I hardly slept a wink, I was so worried. Not about becoming infected – I know HIV is not a death sentence – and if I had the choice of HIV or breast cancer which, a major problem in my family, I'd choose HIV. What I was worried about was my family. Although most didn't need to know if the worst happened, my husband would know. We have a loving relationship and the thought of using condoms again disturbed me – silly, I know, and I'm sure if you asked him he would laugh it off, but it was a real niggle as far as I was concerned as it would be a change in our relationship. I could prevent that or at least try to, by taking these drugs.

'How would I feel if I could have done something to prevent infection but had not done it?'

My husband has always been incredibly supportive of my career. When I started doing this work, HIV was a very taboo subject but he supported me wholeheartedly, despite that fact that when I first got the job there was no treatment for HIV – which meant I was at far more risk than if I had an injury, than now! I was pregnant with our youngest son when I started the job and yet he never once asked if anyone was at risk. How would I feel if I could have done something to prevent getting infected but had not done it? I would be so cross with myself for trying to be brave and, if you like, prove a point ... I know the stats – my feelings aren't relevant here – the stats show a negligible chance of becoming infected. But still – what if I was that 1?

The decision to take PEP is so much more than facts and figures ...

Basically, I felt that if I didn't take the drugs I wouldn't be in control of what happened to me – I think I'm a control freak!

Day 2: Thursday

My husband had been conscious of my tossing and turning all night, and after 20 years of marriage knows me quite well! Once we were both awake, we had a chat and the result was that I decided to take the bull by the horns and take the drugs. My husband's advice was, 'Well, if you're worrying that much, just take the drugs for your own peace of mind'. I should have started them within 2 hours of the injury but they remain effective up to 72 hours later. Therefore, I had to take them within 24 hours – for my own peace of mind if nothing else. I knew side effects could be horrendous, and that a lot of people don't complete the PEP course, but I needed to know that I had done everything I could. I went to A&E, picked up a starter pack at 6.45 and took the medication. I left a message for Occupational Health to phone me and then got on with work. When the OH nurse phoned, she was very supportive and said she would get the medication prescribed. I then got bleeped by the department and told that the consultant would like to see me. I went to see her – and broke down for the first time. I felt silly. I knew the risk was low yet here I was asking for the medication.

'I have never had diarrhoea like this in my life – this is off the Bristol stool chart!'

She was incredibly supportive and made me feel so much better about my decision. I felt enormous relief that I was at least doing something and I will be forever in the debt of that doctor for her support. She told me I was the patient now and needed looking after – I felt very, very safe. She wanted me to go off duty but I did have some patients to see, so agreed to go off early and stay off the next day as we didn't know

how I would react physically or emotionally. I carried on with work and physically I felt fine apart from some diarrhoea. Emotionally, I felt better but was still thinking about what had happened. Later that day I spoke to the regional consultant who also made me feel better by supporting my decision. He said that he and a colleague had discussed it and really didn't know what they would do but thought that they wouldn't take the medication. Then they had discussed me and how rational I normally was ... and then they had gone over it all again and thought, what if we were that 1? He also reassured me about the low risk and told me which baseline and follow-up bloods I would need to monitor treatment, which he was happy to be reported here. I told him that in future my advice to staff in the same position would be to take the first dose and then think about it. He agreed.

When I got home, I told my husband that I was taking the medication. He was very supportive as always. However, I don't think I let him see how it was affecting me until he made a simple joke about sharing cups and I started crying! I was still emotional and realised that the occupational health consultant was right to tell me to take some time off. I decided not to tell my children or my mum what had happened. My mum in particular would have been worried sick and convinced I was going to get AIDS. Even though she knows that people with HIV can live normal lives, she is still haunted by the 1980s campaign and thinks of a tombstone falling over! Overnight I slept well.

'I woke up about 3 am feeling so ill ... I could barely lift my head off the pillow.'

Day 3: Friday

I have never had diarrhoea like this in my life – this is off the Bristol stool chart! No abdo pain, a bit of nausea but diarrhoea like you've never had! Apart from that I feel good and think I'll take out shares in Imodium – great drug! The OH consultant phoned me at home today to see how I was and I went to work to get baseline bloods done and pick up my medication. It hadn't come in so will need to pick it up tomorrow.

Day 5: Sunday

I've missed a day writing because yesterday I just couldn't. I went to bed feeling a bit tired and woke about 3 am feeling so ill. Typical flu symptoms – I could barely lift my head off the pillow. Every joint and muscle was aching, I felt incredibly nauseous, so much so that I could only manage two spoonfuls of cereal to take my medication with. I could hardly put one foot in front of the other when I got up. I took paracetamol and after about an hour, it took the edge off it but I still felt awful. I had promised to take my mum to see her brother in hospital in Swansea (60 miles away) and my son to the cinema but there was no way I could drive that far. I continued to take paracetamol 4-hourly, and did manage to drive to the local hospital to pick up my medication – only to find it had still not come in. I then had to wait in A&E for them to give me another starter pack.

I looked and felt awful and tried to explain to the nurse concerned that all I needed was this medication but I had to register and take my turn. I sat in A&E for 20 minutes feeling dreadful. At the time I thought she was being a 'jobsworth' but looking back now, it wasn't really like that. However, when she gave me the medication, she said that the doctor who'd prescribed it thought I was mad and would never take it. I told her to tell him that I hoped he would never have to make that decision.

'Have been having very vivid dreams. Everything is in colour and feels completely real.'

Spent the day on the sofa in front of the TV, dozing. My mum and the boys now knew what had happened – I felt I had to tell them as it was so unlike me to miss the chance of a day out – they knew I must be really ill and I could see the worry in their faces. They were brilliant, once they knew it was the medication making me feel this bad and that I was purely taking it as a precaution. I managed a bit of supper – then when it came to taking the evening dose, I very nearly didn't. I felt nauseous just looking at the size of the tablets, let alone knowing that I was feeling this bad because of them. I decided I would take them for 1 week and if I still felt really bad, would then stop. The thing that made me take them was that, firstly, studies show that most people stop taking PEP in the first 3 days. I could see why, but was this because they thought the effects were going to continue? HIV patients take these drugs for life, so surely side effects couldn't last that long – or could they? Went to bed and slept like a log.

Felt better when I woke up. The aching was much less – I could function! I ate lunch, which my mum and husband had cooked. I didn't do a lot although I did manage to vacuum and tidy around, which was impossible yesterday and the day before. Went to bed early.

Day 6: Monday

Slept well again. Have been having very vivid dreams each night – not scary, just very vivid. Everything is in colour and feels completely real. Also, considering how much happens, some last hardly any time at all. Had a lovely dream at one point last night where I was looking after my best friend's two-year-old as she went shopping – we did loads of stuff, which took two days ... but when I woke up, I'd only been dozing for 10 minutes! Don't mind this though – feel very refreshed after each dream.

'No diarrhoea since 7 am, no nausea since midday and have eaten roast dinner.'

Went to work. Feel a little bit flu-like but not too bad. Decided to work half a day as had patients to see. Infection control side was very busy but my colleague was lovely, telling me to go home and get a sick note. Can't do this as not ill enough. I was sure that taking half a day would help. Did my work and came home. Felt very guilty as felt good. Will definitely go into work tomorrow and do full day. Need to get back to normal. By time of going to bed at 9 pm have had no diarrhoea since 7 am, no nausea since midday and have eaten roast dinner. Looking up! By the way – eventually got meds from pharmacy.

Day 7: Tuesday

Went to work as normal after another night of very vivid dreams. Feeling a little tired and still having diarrhoea but physically good. Starting to think I over-reacted by deciding to take PEP. In the cold light of day, a week later I am in a far better position to make a rational decision. I can see just how low the risk is to me but I made the decision and will stick with it. Those tablets really are big though!

Week Two

Haven't written every day as nothing new to report. Have fallen into a routine of taking tablets, having diarrhoea soon after and then feeling OK! Feel a bit fuzzy-headed in the morning and realise that is caused by one particular tablet, which needs to be taken once a day – the one I usually tell patients to take at night ('do as I say, not as I do!'). Had bloods checked and all well on the liver and kidney front. Working as normal but going to bed a bit earlier than I usually would.

Week Three

Coping well – nothing new to report.

Week Four

I really cannot wait to finish these tablets now and am again feeling physically sick when I see them. Think this is because I know the risk is so low that I don't really need to take them. Perhaps I would feel different if they were saving my life.

'I can now empathise with patients having to take the medication – on time – every day.'

Post PEP

All well – medication finished, end of treatment has arrived, bloods all normal. I didn't realise just how tired I felt until the medication stopped. I wasn't tired enough to make me stop work but have so much more energy now the course is over. Would I take the medication again in the same circumstances? My head says no – but then I always said no before this incident, which has definitely been a steep learning curve for me. I can now tell patients that I have taken the drugs and do have limited experience – although they may well be on different drugs. I can also now empathise with how they feel having to take the medication – *on time – every day* – and I only had to do it for a short time!

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Beyond the theory: thoughts on midwifery teaching in the context of HIV

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Introduction

This paper offers a personal perspective on issues encountered as a midwifery lecturer teaching student midwives about HIV and pregnancy, and suggests approaches to enhance care for HIV-positive women during pregnancy.

Evidence has clearly established that certain birth and pregnancy interventions, and the avoidance of breastfeeding, significantly reduce HIV transmission from a positive woman to her baby. Allowing for variations in treatment needs and choices of individual women, the chance of transmission to the baby can still be as low as <1%, and HIV is increasingly seen as a preventable paediatric condition. Furthermore, the benefits of diagnosis and access to treatment for the woman herself must not be underestimated [1]. To enable positive women to take advantage of these interventions, HIV testing is now a well-established aspect of antenatal care for those unaware of their status at the time they present to maternity services. Increased knowledge of transmission risks in relation to viral load has broadened the choices for women, within the scope of their individual circumstances. Many more women are today delivering vaginally, while questions are increasingly being asked about the possibility of breastfeeding when viral load is low and highly active antiretroviral therapy is being taken.

Recognising obstacles

In spite of this, the ability of midwives to provide appropriate care can be inhibited by stigma, fear, myth, prejudice and anxieties about breaching confidentiality. These factors are to an extent amplified by the woman's own anxieties about how she is going to be treated when entering an unfamiliar environment and meeting some professionals for the first time. Having in many cases developed a close, consistent relationship with the specialist midwife, it is essential for women to feel confident that they will get the care they need when arriving on the delivery suite in labour. The unpredictability of pregnancy and the commencement of labour can further compound these anxieties for both the woman and the professionals. This issue has become more pertinent as growing numbers opt for vaginal birth, with admission to the labour ward being triggered by the onset of spontaneous labour. This contrasts to the relatively controlled circumstances of a planned

caesarean section, with a date that is scheduled in advance.

Broadening training

There is a lack of published UK research exploring how women with HIV experience midwifery care, and concerns raised by both qualified and student midwives give some insights into the barriers professionals perceive to exist. The current curriculum for student midwives includes sessions focussing on the following areas:

- pathophysiology of HIV
- impact of HIV on pregnancy
- impact of pregnancy on HIV
- care of HIV-positive pregnant women

However, having taught both qualified and student midwives, I feel strongly that training for midwives to care for pregnant women with HIV should also include sessions exploring feelings and attitudes in a constructive way, to allow honest communication and dialogue.

Addressing frustrations

Student midwives often bring to the session anecdotes and experiences from practice and in some instances describe situations that left them frustrated or concerned about quality of care. These anecdotes provide a useful platform to address specific concerns and generate discussion. Student midwives, and to an extent qualified midwives, express frustration over feeling de-skilled or excluded because care of this client group is managed by 'specialist midwives'. While it is not the intention to question this model of care, it is worth considering strategies to enhance the understanding of student, and therefore future, midwives in the care of pregnant women with HIV. The current model in some trusts, where specialists undertake the majority of care for these women, means that certain aspects of care present few opportunities for student involvement in practice – and when asked which areas they wish to discuss further, students invariably want to know more about:

- mechanisms for giving positive results
- treatment options
- follow-up of the baby
- feeding options
- disclosure of HIV status to partners

Identifying referral pathways, becoming familiar with care plans and protocols, and having the opportunity to spend time with the specialist midwife in practice, goes only some of the way to addressing these issues.

Building awareness

Upholding a pregnant woman's confidentiality is fundamental to providing appropriate care and developing trusting working partnerships between women and their midwives [2]. This standard, while generally accepted and taken for granted as good practice, can present midwives and students with complex feelings and dilemmas if a woman has not disclosed her HIV status to her partner. This issue can manifest on two levels: firstly, a concern that appropriate care and documentation is compromised by the presence of a partner who does not know the woman's status [3]; secondly, an emotional response in some students that failure to disclose to a partner is morally wrong.

Teaching sessions provide the opportunity to explore these feelings. Giving students the opportunity to think about their own circumstances, and what they would do in relation to disclosure, helps raise awareness about the dilemma that many women face. These sessions can be further complicated by the fact many students originate from countries with high HIV prevalence. Exploring feelings and anxieties about HIV, whether conscious or unconscious, brings greater understanding of what some newly diagnosed women may face.

The use of anecdotes from practice provides useful insights and can emphasise a point (Panel 1). Giving examples of real scenarios can enable students to consider the issues and generate plans of care that take into account the specifics of individual women's stories.

Developing strategies

From a practical point of view, there is concern that confidentiality will be breached if the partner asks questions about, for example, the baby's medication or why his partner is not breastfeeding. It is important that students and midwives include women in planning how to manage these situations. Whilst it is the responsibility of the professionals to maintain confidentiality, women must be given the opportunity to say how they would want professionals to answer these 'difficult' questions when disclosure has not yet happened. It is interesting to note that the underlying ethos of working in partnership with pregnant women can be undermined when midwives feel their usual ways of practising are challenged. They can be anxious about what to do if a baby's medication is due during visiting time, for example. The realisation that they can ask the woman in

Panel 1: educational scenario

A very effective story is the one about a young woman diagnosed in pregnancy who had disclosed to her partner. He was supportive, but their situation was further complicated because they lived with his mother. The woman was clear that her mother-in-law would be very angry if she knew her grandchild was not being breastfed and always fed the baby in the bedroom so her mother-in-law did not realise. In spite of the husband being aware of his wife's status, he was not able to stand up to his mother and support his wife.

This complex but not uncommon scenario illustrates to students the challenges some women face when attempting to follow advice to protect their babies. Many HIV-positive women will want to breastfeed but will follow advice not to, in order to minimise the chance of transmission to the baby. Raising awareness of this concept can enhance midwives' understanding and enable them to think about the kind of support women need to formula-feed their babies safely. This may include practical support, such as the provision of sterilising equipment and access to formula milk; and emotional support associated with the complex feelings of not breastfeeding [4].

advance how she wants this dealt with greatly reduces anxieties and ensures appropriate care for the baby, whilst also keeping the woman at the centre of decision-making.

Women will usually have had the opportunity to discuss disclosure at length with the specialist midwife or another member of the HIV team, following diagnosis and in the lead-up to the birth of the baby. They will have been encouraged to consider their own responses to difficult questions about feeding, medication and mode of delivery. Again, midwives and students tend not to be involved in these discussions so may be unaware that essential work and support around disclosure is happening in another part of the multidisciplinary team. Confusion can thus arise over roles and responsibilities in terms of disclosure to partners, particularly when this impedes the ability to provide appropriate care.

Gaining perspective

Midwives meet women for a brief but significant period in their lives. Those diagnosed with HIV antenatally have a timeframe dictated by the pregnancy to make major decisions related to treatment, delivery, feeding and disclosure. It is essential that midwives are aware of the processes that individuals go through following diagnosis – and understand that at this stage it is still 'very early days' in terms of coming to terms with diagnosis, because disclosure tends to be a complex process rather than a single event [5,6]. It is important to point out to students that women will continue to

have HIV once their encounter with maternity services has ended, and their reactions to their diagnosis will evolve and change as they become adjusted to their circumstances. There is understandable frustration that midwives are often not fully aware of outcomes for these women and their babies when they have been instrumental in their care at such a significant time.

The psychosocial ramifications of HIV complicate the provision of appropriate care, especially as a large multidisciplinary team is often involved, including a specialist midwife. Work with both student and qualified midwives has shaped my own view that, although familiarity with referral pathways, policies and protocols is essential, we must look beyond this to achieve a high standard of efficient and compassionate care in the context of HIV.

Looking ahead

Both student and qualified midwives experience anxiety over misjudging care responses for this client group, particularly in the areas of confidentiality, documentation and answering 'difficult' questions. Midwives have traditionally been central to the care of the women they work with, and it is thus the vision of Midwifery 2020 that the midwife is either the lead professional in cases of low-risk pregnancy where a normal birth is expected with few interventions; or acts as care coordinator where there is wider multidisciplinary team involvement. This may be where an obstetric complication presents a higher level of risk or where the pregnancy is complicated by an existing medical condition (HIV being one of many possibilities) [7].

Midwifery curricula are required to be redesigned and approved by the Nursing and Midwifery Council (NMC) every 5 years [8] to ensure that practitioners are able to meet the changing needs of childbearing women. Educationalists should respond to views and feedback from existing students and users of maternity services when re-assessing curriculum content. The current model of care for HIV-positive women has many advantages but does to an extent exclude

midwives and student midwives from full involvement in care.

Student midwife training should include time in sexual health clinics, participation in multidisciplinary meetings and following an HIV-positive woman from diagnosis through to the postnatal period and testing of the baby. This will increase awareness and understanding of roles and responsibilities of individual team members and give students a more direct understanding of the processes involved following an HIV diagnosis. Greater involvement by midwifery students in the care and support of HIV-positive women will allow them to see the full picture and allay anxieties that they may 'get it wrong'. The result must surely be improved outcomes for both mothers and their babies.

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Abstract 01

Psychological support study 'my brave face is false'

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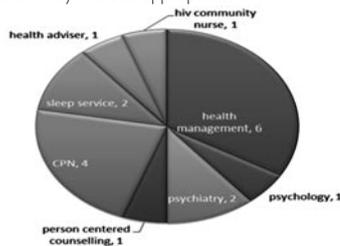
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Background: The recently published MEDFASH 'standards for psychological support of adults living with HIV' states that the prevalence of psychological and psychiatric problems among people living with HIV is substantially higher than in the general public. People with HIV are about twice as likely to be diagnosed with depression as matched controls in the general public. Cognitive impairment is also higher amongst people living with HIV than in the general public, and is an early risk factor for early death, poor adherence, poorer functioning of daily life and loss of employment. With this in mind it was identified that patients being admitted to the in-patient unit presented an ideal opportunity to assess their psychological needs and their experiences of services/interventions and consider what may have helped them in the past and refer where necessary into the appropriate service.

Methods: 29 voluntary self-completed questionnaires were used to introduce the subject, followed by a structured interview. The interviews took part at a mid-point of their residential stay to allow for further support if required. Quantitative data was recorded by the number of referrals made and qualitative data measured by the client's responses.

Results: There was a broad range across the whole scale when asked if satisfied with how they are coping with their illness. Predominately clients reported they had accepted their illness, but a high proportion reported feeling sad. Surprisingly 81% clients reported feeling unsatisfied with their sex life's when this was explored in more depth, reasons given were, 'I worry about disclosure', 'I worry about passing on the infection', 'I don't deserve a partner', 'I have no sex drive'. 14 appropriate referrals were made into psychological services (48%). 11 patients felt their needs were being met already (38%). Referrals were made for all patients requesting them and agencies felt they were all appropriate.

Referrals made



Conclusions: This study resonates with issues raised in Standards for psychological support. There is a need for services to define mental health packages, screen regularly and involve patients in local service development. The relationship between sexual well-being and general well-being is strongly highlighted in this study. The screening tool operates as a therapeutic process within its own right and allows patients time to discuss their anxieties and have them acknowledged.

Abstract 03

Barebacking: opinions of HIV-positive men who have sex with men

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Background: Men who have sex with men (MSM) remain disproportionately affected by HIV and sexual infections, acquired predominately through condomless anal sex (CAS). HIV positive MSM have higher rates of acute STIs than their heterosexual counterparts which increases the risk of HIV transmission in discordant sexual encounters. A better understanding of the influences that affect HIV positive MSM and their decisions to engage in CAS is required for more effective health promotion

Method: MSM were targeted via gay press and leafleting, to complete an online questionnaire exploring issues around CAS. Following ethical approval data was collected from November 2010 to October 2011. Responses were reviewed thematically to explore opinions and motivations for CAS in HIV positive MSM.

Results: These data are drawn from a larger study. A total of 57 males met the criteria; the median age was 37 (range 23-58), with the majority being White British (n=38). All had engaged in unprotected anal sex, but only 24 identified themselves as barebackers. In the previous 12 months 21 were diagnosed with an STI, 9 with HIV. Barebacking was identified as contextual (e.g. in relationships); as an identity (e.g. I am a barebacker) and as a behaviour (e.g. I bareback). Participants opinions on CAS identified it was acceptable if consensual, it allowed better more natural sex and increased intimacy. However its associated risk, in particular Hepatitis C and acquisition of different HIV strains was acknowledged. The most common themes identified as personal reasons for engaging in CAS were: physical sensation, transgression and sero-concordance. Participants also reported engaging in sero-adaptive behaviours such as sero-sorting or condom sorting. Yet, on the last occasion of CAS discordant sex was reported by 13 participants with regular partners and 6 with casual partners. A further 15 reported CAS where the HIV status was presumed positive and 11 where the status was unknown.

Conclusion: This study has shown that there are a variety of reasons why this population engage in CAS, and remains a complex issue. HIV positive MSM are endeavouring to engage in concordant CAS and utilise sero-adaptive strategies. These decisions can be based on assumptions of status and an individual's responsibility, making discordant sex common. When tailoring risk reduction strategies with patients it is important to recognise this and the role that intimacy plays in CAS.

Abstract 02

Evaluation of a patient satisfaction survey following screening for HIV related neurocognitive impairment (NCI)

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Background: Despite antiretroviral therapy, neurocognitive impairment (NCI) remains prevalent with asymptomatic neurocognitive impairment (ANI) the most common form of NCI seen at screening. However screening for ANI is controversial with concern over the anxiety caused either by screening or diagnosis and no clear management of the condition when identified. We offer a routine unselected screening service for those infected with HIV as well as a cohort study for 18-50 year old men who have sex with men (MSM). We distributed a post NCI screening service evaluation questionnaire to assess satisfaction and anxiety.

Methods: Subjects were HIV positive and aged 18-50. They were screened for NCI and anxiety/depression using the Brief Neurocognitive Score and International HIV Dementia Score as well as undergoing screening for anxiety (GAD7), depression (PHQ9) and memory (EMQ). On completion they were either reassured that the tests were normal or were referred for further investigation. Following assessment subjects were asked to complete an anonymous satisfaction survey.

Results: 101 neurocognitive screen surveys were analysed. Overall satisfaction was high with 50% saying they 'felt better' following screening. 43% said it 'made no difference' and only 6% stated it 'worried me'. On a scale of 0-10 of helpfulness, the mean score was 7.53. The strongest emerging theme was reassurance following assessment.

31 subjects indicated that they were referred for further investigation and 46 subjects that nothing else was needed; 8 reported they did not know and 16 did not respond. Satisfaction was not significantly different in these groups with those referred on, rating satisfaction out of 10 at a mean of 7.54, and those with normal screen as 7.09 (p=0.46).

Of the group that were referred for further investigation, only 6% said the test 'worried them' compared to 4% in the non-referred group. 49% said they 'felt better' despite an abnormal result compared to 50% in a normal screening result (p=0.76).

Conclusion:

Despite concerns around screening asymptomatic HIV positive patients for NCI, this service evaluation showed high satisfaction. The majority found it helpful and most felt better following screen. Very few commented that it 'worried me', even in the group that were given an abnormal result and referred on for further testing. The results suggest that screening for NCI by this method is acceptable and helpful to patients and concerns about creating undue anxiety by screening and referral are unfounded.

Abstract 04

Promoting user involvement through holistic nursing framework for the care and management of people with HIV/AIDS as a chronic condition

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Background: Until recently, patient-client participation has played limited role in the assessment, planning and delivery of care in the National Health Service (NHS). Opportunities for patients' involvement in decision making within the NHS was provided by the formation of primary care groups (PCG). The PCGs core focus on health improvement required looking beyond traditional professional-client relationships and concentrated on forming partnerships with local populations. In this regard, PCGs and Primary Care Trusts (PCTs) were required to pursue initiatives for involving patients and the public. Other areas of healthcare including Genitourinary Medicine (GUM/HIV outpatient clinics followed this trend. Users, for the purpose of this research refer to HIV positive adults (18 years or older) that are registered and regularly use the GUM clinic as the main point of accessing HIV care and management.

Aims: The aims of this qualitative research are:

1. To identify the barriers to forming and maintaining HIV service users' involvement group from the perspectives of HIV positive patients
2. Ascertain the role of nurses working within HIV services in establishing and maintaining successful user involvement groups using holistic care framework for a chronic condition such as HIV

Method: A favourable ethics opinion was obtained from the local NHS Ethics Committee. A one and a half hour focus group interview was conducted and thematic analyses of data undertaken. Because the care and management of people living with HIV as a chronic manageable condition necessitates whole person care, the holistic perspective was used as theoretical framework to guide data collection and analyses.

Results: Four themes emerged from the analysis of the research data including Naming the group, involving the multidisciplinary team, peer support and developing the group. However, the overarching or all embracing theme here was power. This is attributed to the rationale that participants want their perspectives included to influence the way their HIV condition is managed as a "whole".

Conclusion: HIV has emerged as a chronic manageable condition. Hence neither a dominant medical model nor nursing interventions alone could address the diverse care needs of patients living with HIV. Hence a holistic framework, which also seeks to understand the perspectives of patients and family members, is appropriate for the nursing care and management of people living with and affected by HIV.

Abstract O5

HIV healthcare in the future: where do nurses fit in?

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Background: As HIV becomes a more manageable condition for many patients, new service models for stable and complex patients and for primary care are evolving. This research aims to explore current and future models of HIV healthcare to identify sustainable options for HIV service delivery including roles for HIV nurses.

Method: A grounded theory approach was utilised across 3 HIV service sites of different size, location and service specification. Following ethics and R&D approvals, data from semi-structured interviews with 13 HIV patients and 20 healthcare workers in HIV were transcribed and analysed using a constant comparative method and a dimensional analysis strategy.

Results: Overall, HIV healthcare services were perceived as different from other health services by all participants. This sense of 'special' identity influenced individual attitudes to service changes and the ability to adapt to new models of HIV healthcare. Relationships between patients and healthcare workers in HIV were highly valued and participation was a key factor in keeping patients engaged in care.

The majority of patients identified as being clinically stable but also described an all-pervading nature of HIV on their physical, psychological and social well-being that was irrespective of age, gender or length of diagnosis. There was a wide range of patient confidence in dealing with these fluctuating health issues and this to some extent determined HIV service utilisation. Expectations of non-HIV services were often based on the high standards of HIV healthcare reported by participants, although those who were younger and more recently diagnosed appeared more likely to consider new models of care.

Nursing roles and levels of practice were largely influenced by the numbers of doctor posts or volume of patients but there were high levels of support for nursing roles across all participants. Support, specialist advice and psychological care were the key elements of nursing roles irrespective of role description.

Further verification and data analysis will be undertaken.

Conclusion: As HIV services continue to evolve, some patients may require transitional support to access new services. Likewise, future models of care will need to incorporate the spectrum of needs for clinically stable patients and nurses may be key players in providing this.

Abstract O6

The establishment of an annual health clinic

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Background: The BHIVA guidelines state that specific investigations and assessments need to be carried out regularly to maintain the health of people living with HIV. Following a presentation at NHIVNA regarding the set up of an Annual Health Clinic (AHC), a similar model was adapted for local use. Following the commencement of this clinic an audit was conducted against professional guidelines to determine whether this clinic was an effective intervention. The clinic is nurse-led, multi-disciplinary, and a "one stop shop" where the patient is aware they will be seeing various specialities for screening, which reduces missed opportunities to screen during routine standard care.

Method: The draft BHIVA guidelines "Routine Investigation and Monitoring of Adults with HIV-1" and the European AIDS Clinical Society Guidelines 2011 version 6 were used to establish the standards to set the audit against. A retrospective audit of case notes has been undertaken following the random selection of fifty patients who had attended AHC and fifty patients who had attended for standard care over the same time period.

Findings: The preliminary findings of this audit are that patients who have been seen in the AHC are much more likely to have had all routine annual screening completed than those who have attended for standard care. An example of this is of those women who attended AHC, 100% were offered cervical cytology compared to 43% of those who attended standard care over the same time period. EACS guidance recommends mood screening every 1-2 years and the AHC has enabled this with 98% completing the Hospital Anxiety and Depression Scale and being offered follow up for anxiety management and relaxation training where a need is identified. In comparison, the standard care group had no mood screens completed.

Conclusion: The pilot audit findings have shown that the AHC is successful at ensuring guidelines regarding patient care are met in one clinic visit. It has been instrumental in the diagnosis of significant cognitive deterioration and other conditions which would otherwise have gone undetected or taken longer to be recognised. This has allowed prompt treatment which should improve patient outcome.

Abstract O7

Identification and management of patients who are newly diagnosed with HIV and subsequently lost to follow-up

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Background: The provision of optimal HIV care and regular clinic review can help reduce the risk of HIV-related morbidity and mortality among persons living with HIV, as well as the risk of HIV transmission. Recently, the HPA has suggested monitoring rates of loss to follow-up (LFU) from HIV-services as a quality of care indicator. Our clinic does not currently have a uniform local policy on identifying newly diagnosed patients who are lost to follow therefore we present here the results of a local audit of all patients newly diagnosed with HIV in a 1 year period and management of patients who subsequently were lost to follow.

Methods: All patients who were diagnosed with HIV infection between January 2011 and January 2012 were retrospectively selected for the audit. Using electronic patient records, we assessed 1) the age of patients who were LFU within the 1st year of diagnosis 2) whether these patients were truly LFU or transferred to another centre 3) whether contact had been attempted 4) the outcome of this contact and 5) the CD4 count of patients who were LFU.

Results: 497 patients were newly diagnosed with HIV during the period studied. Of these, 91 (18%) patients were identified initially as potentially LFU as they had not been seen in the clinic since diagnosis or their 1st appointment with the HIV service. 26/91 (29%) had documented transfer of care letters to other centres in their records. 1 (1%) patient had died. 6/91 (6.6%) have since re-engaged with services. 5/91 (5%) were diagnosed with HIV in prison and no further follow up is documented however these patients activity is generally entered elsewhere. 3/91 (3%) are documented as currently overseas and have not been seen within the past 6 months with no follow-up booked. Median age of those who had been truly LFU was 31 (range 19-59); 2/51 (4%) were female. Median CD4 count was 483 (range 224-1006). 19/51 (37%) patients were contacted by the clinic either via letter, phone call or text message – this ranged from 1 voicemail left to - in 1 case – 3 phone calls, 2 recorded delivery letters, and 1 text sent. None of these 19 patients re-engaged.

Conclusion: Robust local protocols are essential to ensuring that patients who are lost to follow up are identified and contacted appropriately. However, ensuring that the patient's contact details and ideal mode of contact are correct is crucial. Nurses and health advisors are ideally placed to forge links with other centres to share information and concerns about patients who are lost to follow up.

Abstract O8

Improving nurses' knowledge about HIV: development and evaluation of an innovative online resource

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Background: Poor HIV-related knowledge is associated with discrimination towards people living with HIV/AIDS (PLWHA) in healthcare settings. The increasing prevalence of HIV in the UK and shift of HIV care into generalist settings means that more nurses will be caring for PLWHA. Therefore, improvement of nurses' HIV knowledge is important to ensure high quality care. Many nurses may not have been exposed to HIV patients and may not have had significant HIV-related training. This abstract reports on an educational research project that developed and evaluated an innovative e-learning approach to post-registration HIV education.

Methods: An evidence based Reusable Learning Object (RLO) was developed and delivered to 12 nurses as part of an undergraduate nursing research project. RLOs are short, multimedia, interactive educational tools valued for their flexibility and accessibility. The study aimed to investigate the RLOs' effectiveness by measuring changes in nurses' HIV-related knowledge scores through a pre/post-test design. Scores were compared with a non-RLO comparison group of nurses (n=12). Independent t-tests were used to establish if the change in knowledge score was significant.

Results: Prior to the intervention, all nurses' HIV knowledge was very poor, with a mean score of 9.11 (± 2.5) out of 20. The RLO group increased their score by an average of 6.5 (± 2.8) marks compared to the non-RLO group (mean increase 0.3±2.1). The RLO groups' increase in knowledge score was statistically significant (p

Conclusion: Although small scale, this study is the first of its kind to provide quantitative evidence that RLOs can significantly improve nurses' knowledge. The findings suggest that, in light of nurses' poor HIV knowledge, post-registration HIV education must be a priority and can be easily delivered via a short RLO. In future, HIV nurse specialists will increasingly be called upon to educate generalist nurses in providing HIV care. This open-access RLO may prove to be a useful resource for this aspect of the HIV nurses' role. Further research is required to assess whether changes in knowledge and attitudes are sustained over time.

Abstract 09

How does the changing role of the HIV nurse impact on job satisfaction?

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Introduction: Since the introduction of antiretroviral therapy to treat HIV, the disease area has rapidly changed. HIV is now considered a long-term health condition in the UK, characterized by periods of illness. Increased cohort sizes, organizational changes and workforce configurations have lead to multiple changes to the HIV nurses role.

Objective: The aim of the survey was to gauge professional opinion regarding how nurses were feeling about their current role, how skilled they felt within their role and how they coped with work related pressures.

Methods: A survey was sent to NHVNA, North West alliance members and nurses at North Manchester General Hospital who worked with HIV positive patients.

Results: Out of the 49 surveys' completed 22.4% (N=11) were male 77.6% (N=33) female. The majority of the respondents had been qualified for 20+ years 57.1% (N=28) providing care for HIV patients for a variety of different time frames, 0-5 years, 26.5%(N= 13), 5-10 years 26.5%(N= 13), 10-15 years 8.2 %(n=4) 15-20 years 18.4% (n=9), 20+years 20.4% (n=10). 85.7% (n=42) felt their job had changed significantly within the past 2 years with 61.7% (n=29) stating there was no career progression within the organization where they worked.

42.6 % (n=20) felt they had received a moderate amount of training for their current job, 21.3 % (n=10) reporting receiving a lot of training, 21.3% (n=10) receiving a little, 4.3% (n=2) receiving no training, with surprisingly only 10.6% (n=) stating that they received a great deal of training. The vast majority of respondents 77.1% (n=37) stated that they felt they had a good work life balance 56.3% (n=27) felt rested after their days off. In a typical week HIV nurses predominantly felt a moderate amount of stress 44.9% (n=22). Encouragingly, 59.2% (n=29) did not feel burnout by their work. Practitioners were asked about the level and type of support they had in relation to their job 52.1% (n=25) felt they received enough support. Types of support were varied with the majority of support coming through informal support and peer support (68.1 N=32). With only 31.9% (n=15) reporting that they had clinical supervision.

Discussion: A significant number of nurses felt that their job role had changed within the last 2 years. Nurses stated a variety of different reasons for these changes, common themes to emerge were increased emphasis being placed on value for money, increasing case loads, less patient contact and more paper work.

Abstract 011

Clients' knowledge of PEP, criminalisation and safer sex

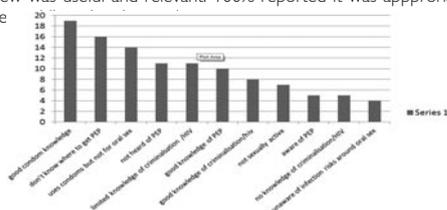
C Lovett

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Background: A large quantity of information is often offered to clients at the time of diagnosis and this study looked at what information is retained, updated, useful and meaningful. This is an important intervention in the reduction of onward transmission.

Methods: The method used was a voluntary semi-structured interview with 25 clients, followed by a client acceptability questionnaire. The interviews provided a platform to ascertain the knowledge and awareness clients had. Where there appeared to be a knowledge deficit, this was discussed and updated.

Results: There mean time of diagnosis was a high range of 1–21 years. The knowledge base was highly variable and interviews revealed many blocks enabling clients to have a good sex life. Clients expressed feelings of a low entitlement to a sex life, fear around disclosure and rejection, issues of low libido and a general poor self-worth. The client acceptability questionnaire was carried out to make sure that clients were comfortable discussing these issues. They were asked if the interview was relevant to them and if anything else should have been included. 81% stated the interview was useful and relevant. 100% reported it was appropriate to have the interview



Conclusion: This study, although small, has identified there is a knowledge deficit in this cohort. The reduction in onward transmission is an important prevention strategy, and the focus has really shifted in terms of prevention, with a greater emphasis to work with HIV positive clients to enable them not to pass the virus on. Services need to find new ways of engagement with clients and perhaps screen for some of the more common problems, ie lack of libido, low entitlement.

This intervention

- Supports giving knowledge to clients to help them make informed choices
- Motivates – to behave in a certain way
- A chance to look at self-beliefs – a supportive environment is provided where ideas can be tested
- It allows clients to have power and opportunity.

As a result of this study we now have a named nurse for sexual health who ensures these areas form part of the care-planning. We have also started a 'virtual clinic' in terms of sexual health and are able to offer self-tests for *chlamydia trachomatis* and *Neisseria gonorrhoeae*.

Abstract 010

Lost to follow up – how can nurse specialists minimise this?

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Background: Long term follow up for HIV patients is crucial for good management of the condition. Regular clinic visits are not only necessary for the prevention of any complications, but to provide ongoing psychological support. For various reasons, every year a number of patients fail to attend specialist follow up to the long term detriment of their health.

Method: Our database highlighted patients who had not attended in the last nine months. Data was scrutinized by HPS, HPA, Health Records and unit staff. For patients identified as not having sought care elsewhere, their GP practices were notified. Several patients also received an invitation to re-engage. We then carried out a retrospective case note review to determine how to minimise future lost to follow up (LTFU).

Results: 204 patients were identified as being LTFU. Of these: 6 had died, 101 had moved abroad, 47 had transferred care, 7 had registered with a GP elsewhere, and 25 were untraceable. Of the remaining 18 still registered with a local GP, 1 re-engaged via the prison, 1 re-engaged as she was pregnant and 1 is a long term non-progressor therefore attends every 2 years. The GPs of the remaining fifteen were contacted. Eight patients received letters. Appointments were sent to seven at their request and four attended. Three have restarted therapy. Two of them had a CD4 less than 50, one has a CD4 less than 200. The three who did not attend were sent another appointment. We await contact from the remaining six. The average time from when a patient last attended was 30 months. On average they were offered 3.69 appointments each, missing a total of 48 appointments. Engagement following DNA's was analysed, illustrating that contact was successful following only 27% of the DNA's.

Discussion: The final number of patients genuinely LTFU was relatively low (2.45% of our total cohort). However, 75% of those who have returned to care have very low CD4 counts. Specialist nurses now call patients who DNA appointments, and further appointments without contact established will be limited. Reminders before appointments are also offered. Our database has been altered to clearly identify patients who are known to have left our care. It now also highlights those who are LTFU on a six monthly basis so that this can be reviewed regularly to continue to minimise numbers of missed appointments and ensure patients under our care remain well on therapy.

Abstract 012

Perpetual spirals of power and pleasure: exploring the life experiences of gay men living long term with HIV into the twenty first century

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The aim was to explore the life experiences of gay men living long-term with HIV.

Methods: This aim was achieved by means of an in depth analysis of a small number of life history interviews. 'Thick description' is used as a way of achieving external validity, providing context and meaning. The author's relationship with HIV forms one methodological issue, as does the continuum of involvement of relationships between the researcher and the researched. Narrative analysis of the narrative structures also identified which narrative models were employed.

Results: Themes which are analysed include coming out narratives in the context of sexuality and of being HIV positive. Coming out is shown as a process of moving to a positive or accepting sense of identity as being gay, or as being HIV positive. Coming out and other sexual life stories are shown to be part of the political process, embodied in the concept of intimate citizenship. The three generic elements of suffering that gives the plot tension, an epiphany, and transformation into a survivor, are identified. The epiphany leads on to another stage of life and involves a development of consciousness and of identity. It is suggested that sero-conversion for a person with AIDS/HIV can be seen in terms of a Giddensian "fateful moment" or a Denzinian "epiphany". These coming out narratives describe a circular life journey, ending in a finding of family or of coming home. The topics of identity and existential angst, linked to disconnection, self-esteem and mental health issues are examined, as is the creation of a positive identity and shift in consciousness. Power including abuse/ violence and other traumatic personal relationships, and sex and love are analysed in the light of the theories of Foucault and Plummer. As well as the power of one individual over another, also present are stories of personal empowerment. The power of sharing information, and the power that not telling can have, is a dominant theme in the narratives, as is the interconnection of power with sex.

Conclusion: This Life History Research dissertation paper is of significance to nurses working with HIV positive gay men. It tells of the traumas and struggles that many have been through and the long journeys of coming out and personal empowerment. Power, narrative, identity, self-esteem and mental health are key issues.

Abstract P1

Survey of advanced practice roles in HIV nursing

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Background: The role of the nurse in HIV care has developed over the past few years, with nurses now having more extended roles. Recent debates have explored the role for advanced nursing practice in HIV but there remains little evidence of the breadth and extent of advanced practice in the United Kingdom (UK) within the HIV setting. The aim of this study was to gain further understanding of the variety of HIV nursing roles in the UK in relation to pay grades and level of nursing practice.

Methods: An anonymous online questionnaire using survey monkey was sent out to all NHVNA members. Data was analysed using Excel and benchmarked against the Royal College of Nursing (RCN) competencies for advanced practice.

Results: 67 responses were received from a variety of nursing roles clinical nurse specialist (CNS) 47.8%, nurse practitioner 7.5%, advanced nurse practitioner / advanced CNS 4.5%, health advisor 17.9%, staff nurse 3.0%, research nurse 6.0%, adherence nurse 1.5%, nurse consultant 3.0%, clinic manager 9.0%. Overall 88.1% of participants reported making health assessments using highly skilled knowledge and skills and 92.5% felt they had a supportive role in helping people to live with illness. 77.6% of all respondents reported making professional autonomous decisions and this function was more commonly reported in clinical nurse specialist roles, with all advanced practitioners and nurse consultants reporting this function. Just over half of respondents (56.7%) were making a differential diagnosis, this was reported more in clinical nurse specialist roles. Out of the 14 nurse prescribers, 9 were making a differential diagnosis. Almost all participants (98.5%) had a health education function to their role with 82.1% screening patients for disease risk factors although the level of practice was not specifically explored in relation to this. Under one third of respondents undertook the ordering of investigations (32.8%) and had the authority to admit or discharge patients and these activities were reported by all advanced practitioners and nurse consultants, whilst only 13 of 32 nurse specialist reported this activity.

Conclusions: This study has highlighted the variety of nursing roles in HIV across the UK. While many reported functioning at advanced practice levels, only 3 were advanced practitioners and there was apparent inconsistency between job roles and pay. The study found that despite RCN competencies and agenda for change guidance there is a lack of consistency between roles and pay.

Abstract P2

Audit of patients with HIV moving in and out of Lewes Prison

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Background: ESHT provides a CNS-led HIV service to HMP Lewes, a category B prison housing 742 men. The National AIDS Trust has produced standards for HIV care in prisons in the UK. People with HIV can be unexpectedly imprisoned, moved to different institutions or released at short notice. These can interrupt HIV care including adherence to antiretroviral therapy.

Method: an audit of 19 consecutive cases was performed reviewing the prison service healthcare electronic record (ER) and written notes.

Results: 5 out of 13 patients on ART had a treatment interruption; 3 out of 19 waited more than one month to see the CNS; 13 patients' treatment centres sent a summary; 18 patients had a summary sent to their next treatment centre or the ER followed them; all those requiring it left prison with 30 or more days' ART.

Conclusion: Treatment interruption during admission to prison is common; there is scope to improve communication between HIV treatment centres and prison healthcare for people with HIV. HIV nurses are in a key position to improve this, possibly through the production of a communication tool. I would be willing to help to develop this with other HIV nurses working in prisons and NHVNA.

Abstract P3

Recovery of haematological markers in human immunodeficiency (HIV-1)-infected patients following treatment for hepatitis C (HCV)

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Background: Dual therapy with pegylated interferon alpha (PEG IFN α) and ribavirin remains the gold standard treatment for HIV-positive patients infected with HCV. However, this treatment is more hazardous in HIV-infected individuals due to an increased risk of immunosuppression, bone marrow toxicity and interactions with highly active anti-retroviral therapy (HAART), potentially resulting in hepatotoxicity and decreased efficacy. While decreases in CD4 count, neutrophils count, haemoglobin (Hb) and platelets have been widely documented, time to recovery of haematological markers has been less well studied. Establishing the time to recovery of these haematological indices would provide clinical staff and patients with information and realistic expectations thus improving the patient experience. We aimed to review the time taken for haematological markers to resolve following treatment with PEG IFN α and ribavirin in a prospectively-followed cohort of HIV-positive individuals with predominantly early HCV infection.

Methods: 67 HIV-positive patients with HCV infection presenting to a single centre between January 2008 and December 2010 were treated with 24-48 weeks of pegylated IFN α and ribavirin and followed for up to 72 weeks. We analysed CD4 count, Hb, neutrophil count and platelets during the 6 month period after therapy.

Results: The overall SVR rate was 81%. All patients were male and the mean age was 38 years (95% CI: 37-40). 70% were treated within 1 year of HCV infection and 79% received HAART prior to HCV treatment.

The mean CD4 count decreased from 626mm³ at baseline to 398mm³ at the end of treatment (p3 (significantly higher than the 140mm³ drop reported in the international Apicort study) This increased to 569 mm³ at 3 months and 642 mm³ 6 months following the end of therapy. Neutrophil, Hb and platelet levels recovered by 6 months of therapy.

Conclusion: Haematological markers, including CD4 count remain abnormal 3 months following treatment for HCV in an HIV-1 positive cohort but recover by 6 months.

Abstract P4

Recruiting patients with HIV to research studies in a London NHS clinic. Clinician perspective-motivating factors and barriers

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Background: A lot more is understood about HIV today due to the amount of research that has been done over the past 30 years but the changing epidemiology of HIV infection means that there is an increasing disconnect between those who have traditionally taken part in clinical research (mostly Caucasian men having sex with men) and those who carry an increasing burden of HIV (black Africans, women and heterosexual men). Clinical staffs are gatekeepers for research enrolment. This study explores service providers' perspectives of motivating factors and barriers for research participation of patients with HIV in an inner city UK HIV specialist clinic in which 55% of patients are women, of whom 72% are of Black African ethnicity.

Methods: Members of the multidisciplinary HIV clinical team were enrolled in a mixed methods study using structured questionnaires and focus groups.

Results: 19 staff members participated in focus groups and 20 completed questionnaires. Staff believed that patients participated in research for altruism, interest in research subject, gratitude and destitute patients were more likely to participate because of co-dependence. Reasons for not participating were time pressure, study commitments, life's demands (including work and childcare), poor literacy, confidentiality, disclosure and adjustment issues to HIV diagnosis. Burden of research and lack of feedback from previous studies to both participants and staff was given as a reason for declining future participation. All staff believed that incentives would increase research participation.

Discussion: Clinical staff carry the responsibility for the wellbeing of patients; their primary responsibility is key to research recruitment in healthcare settings. Their perspectives on factors for research participation may result in reduced participation in research studies.

Conclusion: Minimising inconvenience, together with careful planning to minimise overburdening patients with research may re-assure clinical staff. Staff and patients must have a sense of ownership and feedback to engage actively in research.

Abstract P5

UK students' knowledge and attitudes towards HIV

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Background: Both globally and within the UK, young people (aged 16-25) continue to be the group most affected by HIV/AIDS. In the UK, this is considered to be due to an increasingly sexualised culture, inconsistent sex education within schools and a decrease in drug and alcohol prices. There is a lack of up to date research on young people's HIV-related knowledge and understanding in the UK.

This research study aimed to address this gap, and comprised an exploration of university students' knowledge of HIV. The study also aimed to test the hypothesis that greater knowledge of HIV/AIDS would be associated with decreased discriminatory attitudes. The objectives were to establish the knowledge levels of first year university students on the topic of HIV, to establish attitudes held by these students towards HIV/HIV positive individuals, and to ascertain whether there is a relationship between knowledge levels and attitudes towards HIV positive individuals.

Method: A pre-validated questionnaire (developed by the National AIDS Trust and used by them in a large cross-sectional national survey in 2010) was administered to 422 first year university students in 2011. The questionnaire contained both knowledge and attitude questions. A specific scoring system was developed and piloted in order to establish a statistical relationship between students' knowledge and attitudes.

Results: Students from both arts and science subjects participated in the study. Knowledge levels were relatively high, however several misconceptions concerning transmission routes, testing and contemporary treatment scenarios were evident. Attitudes were mainly positive, yet some negative attitudes were present. The results showed that as knowledge of HIV increased, attitudes became more positive. However it was also found that some students held positive attitudes despite having poor knowledge on the subject. Students scored higher on most knowledge questions and more positively on the attitude questions than the national average.

Conclusion: Overall students' knowledge of HIV transmission was good, however there were still a worrying number of misconceptions. The continued existence of misconceptions and confusion around prognosis and testing suggest that HIV health promotion schemes and educational programs within schools and universities need to be improved. Such programmes need to highlight not only the transmission routes, testing options and treatments for HIV, but must also address the stigma currently surrounding the disease.

Abstract P6

Knowledge and attitudes to HIV/AIDS amongst registered nurses

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Background: Nurses need to be at the centre of reducing HIV stigma and not promoting it through ignorance or prejudice. HIV +ve patients should be cared for by those who will not judge them and have the knowledge to ensure they are treated properly. This study aims to evaluate the level of knowledge and attitudes of registered nurses and discover what factors are associated with these scores.

Methods: This cross sectional survey was conducted in a multicultural setting of one NHS Trust in London. A convenience sample of 144 nurses completed the questionnaire. The AIDS Study Questionnaire was distributed throughout the trust and self-administered. Modification was carried out with permission from the author. Sections included knowledge and attitudes to HIV/AIDS as well as HIV testing. Background variables were collected for associations with knowledge and attitude scores. These variables included HIV nursing experience, year of qualification, years working in the UK, country of training, gender, age, country of birth, marital status, job band, religion and ethnicity.

Results: The sample represented (predominately female) nurses from 22 countries and 25 ethnicities. White British nurses made up <0.0001. Small but statistically significant correlations were found between knowledge scores and years worked $r=0.23$, ($p=0.007$) and between knowledge scores and years qualified $r=0.23$, ($p=0.010$). Associations were found between several background variables and test scores including importance of religion, job band, and previous training.

Conclusions: Overall scores were good but individual knowledge questions indicated a lack of knowledge in some areas. Attitudes questions demonstrated a minority with negative attitudes to HIV. By evaluating the factors associated with poorer scores we can target training to reduce knowledge gaps and improve attitudes to patients with HIV.

Abstract P7

Circumcision as HIV prevention in MSM: A review of the literature

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Background: Men who have sex with men (MSM) are disproportionately affected by HIV, facilitated mainly through condomless anal sex (CAS). Since 2005 there has been growing interest in circumcision of MSM as a method of HIV prevention (CMHP). This follows 3 studies on circumcision in Africa which found up to 60% reduction in acquisition in heterosexual men with an estimated 3.7M HIV infections and 2.7M deaths prevented. Therefore the aim of this study is to explore the evidence for CMHP and the wider implications.

Method: Two platforms (hilo & OVID) were searched in November 2011 using specific search terms, restricted to full text in English. Erroneous and duplicate citations were removed, leaving 14 articles and 1 Cochrane review which were transferred to an Excel® database and analysed thematically.

Results: The evidence - While CMHP is biologically plausible to protect against HIV, STIs and some cancers, the evidence complicated, weak and inconsistent. No association between circumcision status and HIV infection was found. CMHP may reduce but not eliminate risk as the most effective mode of HIV transmission in MSM is receptive anal sex. CMHP offers most protection to insertive partners so relies on consistent sexual role, although there are issues with role consistency over time. CMHP alone would not prevent HIV transmission and is not recommended if already HIV positive.

The wider considerations - CMHP is socially sensitive, culturally controversial and raises human rights, legal and ethical issues. There are concerns about the pathologising of MSM, and that targeted circumcision could increase stigma. The removal of healthy skin is seen by some as genital mutilation and may be linked to increased sexual dysfunction and associated CAS. CMHP could actually increase HIV infections through risk compensation as circumcision status may influence an individual's risk assessment and leave some receptive partners feeling pressured to have CAS. While CMHP may be cost effective when compared to HIV treatment, funding it may impact on existing under resourced HIV prevention strategies.

Conclusions: CMHP would be adjunct to other prevention methods as alone it is not enough to prevent transmission and population level impact is unlikely. Some protection at individual level although dependant on being HIV negative, uncircumcised, anally insertive exclusively (and consistently) and willing to be circumcised. Further research is required, although unlikely.

Abstract P8

Adults newly referred to a third sector organisation demonstrate multiple complex factors that jeopardise health regardless of time since HIV diagnosis

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Background: People living with HIV may have complex social and personal factors that impact on their wellbeing and health promotion ability. The aim of this needs assessment is to identify time since diagnosis and presenting needs of adults newly referred to a third sector organization's services and to use those findings to inform service improvement and local HIV policy.

Methods: : During 2011, 218 adults were referred to a third sector organization by telephone. Upon referral a basic screening process identified factors relevant to individual need including: mental health, psychosocial wellbeing, family needs, physical health and practical needs. Initial screening also captured demographic information and time since diagnosis. This information was analysed to identify whether time since diagnosis influenced complex needs in newly referred patients.

Results: Amongst the 218 referrals, 31.3% presented with identified need in all factors (mental health, psychosocial, family, physical health, and practical needs). 11.5% presented with 4 out of 5 needs, 10.1% with 3 out of 5, 11.1% with 2 out of 5 and 19.3% with 1 out of 5. 16.6% either had zero presenting factors upon referral or were missing data. The most commonly presenting need was for psychosocial support (69.7%) followed by mental health (56.4%). While women consistently were more likely than men to present with greater need in all categories, the difference was not significant. Time since diagnosis was not a statistically significant predictor of individual need upon referral.

Conclusions: Adults newly referred to the third sector organization presented with multiple complex needs irrespective of time since diagnosis. Future research should examine clinicians' referral motivations and patterns, and the cost-effectiveness of earlier referral to third sector organizations in terms of preventing long-term barriers to wellbeing.

Abstract P9

Every second counts – audit of waiting times for blood tests in an HIV outpatient service

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Background: Interventions which improve patient experience and satisfaction are key to service transformation. A common NHS complaint is time spent waiting for a blood test to be taken. Changes in nurse staff mix, with appointment of a nursing assistant team (Band 3), coupled with innovation in IT, with roll out of care record system (CRS) allowed introduction of patient held, pre-printed, request labels. Approximately 2400 HIV patients attend this inner city clinic.

Previously, serological requests were recorded in patient notes, which had to be pulled when the patient attended for bloods. Significant time was spent by reception staff finding notes that were not immediately available; with consequences of patients waiting and reception staff not able to perform their other duties.

Methods: A prospective audit of patients attending for blood tests was performed in June 2011. Data on visit date, time, minutes waiting, appointment type (walk in or booked clinic appointment) was recorded. Comments were also recorded if a patient was called but not in the waiting room.

Results: There were 466 patients attending for blood tests (20% cohort). The average (mode) wait was 2 minutes, with a mean of 3.9 minutes (range)

Conclusions: The process of blood requests and waiting times has been transformed in several ways.

- 1) A system not reliant on finding patients notes has released receptionist time.
- 2) Clinicians pre-print future request labels which are brought by the patient and presented at phlebotomy. This ensures only necessary tests are performed and avoids unnecessary investigations. This has pathology cost savings.
- 3) The appointment of a dedicated nursing assistant team has streamlined nursing pathways, freeing qualified staff to deliver other duties.
- 4) Virtual outpatient clinics are popular for stable patients, and short waits for blood tests further improves patient experience.

Abstract P10

Mentoring nurse initiation and management of antiretroviral therapy (NIM-ART) in South Africa

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Background: An experienced HIV nurse from the UK was deployed for three months in 2011 to act as a mentor to nurses learning to initiate antiretroviral therapy in primary care clinics in a small town in the Eastern Cape, South Africa. Previously, serological requests were recorded in patient notes, which had to be pulled when the patient attended for bloods. Significant time was spent by reception staff finding notes that were not immediately available; with consequences of patients waiting and reception staff not able to perform their other duties.

Methods: Mentoring was carried out using local resources. A review of existing pre-ART patient files was performed. Patients lost to HIV follow up were recalled to clinic.

Results: 286 files were reviewed. Only 24% patients had attended the clinics within the previous six months and 20% had not been seen for more than 2 years. Two lay counsellors visited 222 patients to encourage them to return to care. 65/286 (23%) were untraceable, 11/286 (4%) had moved away, 30/286 (10%) declined the invitation, and 8/286 (3%) had died. In the six weeks following the recall exercise, 51/286 patients (18%) returned to the clinics. All patients had repeat CD4 counts and were screened for TB and other opportunistic infections. 13/51 (25%) were started on ART, 1/51 (2%) patient was found to have TB and 23/51 (45%) others were put on INH prophylaxis.

Conclusions: Mentoring plays an important role in training and supporting professional nurses in their workplaces. By establishing accurate and robust management systems guided by tools such as the Adult Care Record, the pre-ART and ART registers, people identified with HIV infection can receive on-going comprehensive care and be started on ART at the appropriate time by nurses. Recall of lost to follow up patients is feasible in a small rural town. Such extended visits by experienced mentors could play a significant part in the future in raising the standard of HIV care in South African primary care clinics.

Please note: this work is being presented as a poster by Maryna Stander (author 3) at the 3rd South African TB Conference 2012 <http://www.tbconference.co.za/>

Abstract P11

Abstract withdrawn

Abstract P12

As HIV moves towards a chronic disease how involved are patients in their own care?

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Background: Changing dynamics within the consumer-led NHS has stretched resources. The governmental drive to encourage people to take more responsibility for their own health needs, challenges to professional patient dynamics in terms of dominance and power and the significant shift within the field of HIV, from a palliative to a chronic disease, have all influenced service provision. The lack of research, particularly in HIV, exploring patient perceptions of changing services and of empowerment models which promote self management of health needs was identified.

Aim: The study will explore whether people living with HIV (PLWH) have developed strategies to manage their healthcare over time. Also to capture the lived experience of people who are accessing healthcare services, focusing on aspects such as self confidence and ability to access and use health care services.

Method: Ethical approval was obtained for this qualitative study. Five focus groups are being conducted. Each focus group will have a maximum of 10 participants. Participants aged 18 or over who have been diagnosed for a minimum of 12 months are invited to participate by using posters in clinical and community settings. Patients can self refer. Prior written information is provided and participants consent obtained. The focus groups are facilitated by nurses from across the network but not within the geographical area they work in. This ensures the nurses are not in a dependent/caring relationship with any participants. A discussion guide, with ice-breaking advice, suggested open-ended questions and prompts, is provided to facilitators. Discussions are recorded, transcribed and then analysed using thematic analysis. This will produce patient identified themes important in the way they manage their changing relationship with NHS services.

Results: The study commenced on 3rd April. Results from 3 focus groups will be included in the presentation. The emergent themes will be outlined and the identification of the coding categories explained.

Abstract P13

Asymptomatic sexual health screening in HIV day ward leads to increased detection of sexually transmitted infections in asymptomatic HIV patientsC Mutedzi¹, A Eboiegebe¹, S Ayre¹¹Imperial College Healthcare NHS Trust, London, UK

Background: In 2008 the British HIV Association (BHIVA) recommended that people living with HIV (PLHIV) under regular care should have an annual sexual health screen, regardless of risk. Prior to June 2009 this service was only provided using a pre-booked appointment system. If no appointment was available, patients would be given priority in the general walk in sexual health department. This resulted in the service not being as responsive to the patients' needs as the nursing team lacked the relevant skills to provide appropriate sexual health screening. Competency based training was implemented in order to achieve BHIVA national guidelines. A walk-in asymptomatic screening service subsequently went live on the 1st of June 2009.

Method: Data was extracted from the clinic's IT system of the entire patients that attended the asymptomatic screening clinic from June 2009 to May 2011 (22 months). The data showed how many patients attended, and which infections they were diagnosed with. The study also assessed frequency of sexual infections during that period.

Inclusion: All HIV patients who attended the asymptomatic clinic

Exclusion: PEP patients and HIV-negative partners

Limitations: 140 patients were not logged on the system as having attended, hence no data obtained.

Results: There were a total of 1553 patients seen during the 22 month period, of which 1035 were males and 518 were females. 50 (3.23%) patients were diagnosed with syphilis, 79 (5.09%) patients with gonorrhoea, 116 (7.47%) with chlamydia, 5 (0.32%) patients with hepatitis B, 2 (0.13%) with hepatitis C, 1 (0.064%) patient with *Trichomonas vaginalis* (TV) and 10 (0.64%) with urinary tract infection (UTI). A total of 30 (1.93%) patients had the same infection twice, 6 (0.86%) three times whilst 2 (0.128%) patients had more than two different infections in that period.

Conclusions: There has been an increased uptake of screening since the service was established. High rates of sexually transmitted infections (STI) in the asymptomatic cohort indicate the need to maintain and improve the provision of sexual health screening in this population. Further safer sex health promotion in this cohort regarding condom use and high risk behaviour could also benefit this group to prevent onward

Abstract P14

Process and psychological findings of implementing a behavioural change programme for adherence in young people with perinatally acquired HIV infection (PaHIV) using financial incentives and motivational interviewing

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Background: Evidence suggests when antiretroviral (ART) adherence is not established in childhood it reflects a range of self-management difficulties which impede intervention from the MDT to establish adherence in later adolescence. 20% of the transitioning cohort fell into this pattern, 2 of whom died aged 20 and 21. Consultation with clients suggested the potential importance of financial incentive (FI). This fits Behaviour Change theory which requires identification of concrete rewards for changing contingencies. Motivational Interviewing (MI) also has established credentials in this area, though study results are equivocal. An Incentive Scheme (IS) was developed with viral load (VL) endpoints combining FI and MI intervention.

Methods: Young people (16–24y) with PaHIV, low CD4 count and significant adherence problems were eligible. IS involved MI at 2 weekly follow up until a drop and then a VL<50 was achieved. Receiving FI was contingent on reaching each goal in the series and attending for MI. Further goals involved sustaining a VL<50 for increasing periods with further MI. An MI pro-forma recorded importance, confidence, adherence and stage of change at each visit, also identification of barriers and potential solutions. Outcome was measured (VL and CD4 count) at exit from IS. The max total FI was £200/patient (£25/£50 for specific goals). Exit interviews gathered additional qualitative data.

Results: 11 enrolled, 1 declined. Median age 19yr (range 16–23), 8 female. 9/11 reached VL<50 and 5/11 sustained to the IS endpoint (6 months VL<50). IS time range 3–20 months, MI range 2–13 sessions, VL<50 time range 0–13 months (10.2 completers, 1.3 noncompleters). There was a significant relationship between the number of MI sessions and success/failure of IS ($P=0.01$), months of VL<50 ($P=0.01$) and CD4 increment ($P=0.026$). These data and qualitative interviews suggest that the mediating factor in success is engagement via reward, rather than reward for adherence directly.

Conclusion: Following this novel intervention, 46% of this highly challenging cohort achieved sustained virological suppression as a result of behavioural changes. Rewards appeared to encourage attendance. This in turn allowed psychological intervention to identify emotional and logistical solutions for this vulnerable group. The nature of the intervention needs further tailoring in line with behaviour change theory and further directions will be outlined.

Abstract P15

Confidentiality: a continuing barrier to disclosure of HIV status to GPs? The experience and concerns of HIV patients in an integrated sexual health clinic

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Background: Existing data from large HIV centres exploring the relationship between HIV services and primary care demonstrate a high level of GP involvement. In 2008 we surveyed the patients attending our HIV service and found that a significant proportion had disclosed their status to their GP. Confidentiality was given as the commonest reason in those who had not. In 2011, following concerted efforts to encourage and support patients to disclose their status to their GPs, we repeated the survey with the aim of assessing ongoing barriers to communication with primary care. **Methods:** Patients attending our HIV outpatient centre between the end of March and July 2011 were asked to complete a form documenting their consent for communication between the clinic and their GP and to complete a questionnaire detailing their experience of Primary Care services.

Results: 102/120 (85%) questionnaires distributed were completed. 79% of patients gave consent for the clinic to contact their GP and 75% stated that their GP was already aware of their HIV status (compared with 76% who stated they had already informed their GP in 2008). 14% were registered with a GP but had not disclosed their status, of whom, 72% gave confidentiality as the main reason for their non-disclosure (compared to 50% stating confidentiality was the main reason they had not disclosed in 2008). Of all the patients who completed the questionnaire, 32% had concerns about attending their GP which related to their HIV status. Concerns expressed included confidentiality (39%), lack of GP HIV specialist knowledge (22%) and stigma (13%). 22% of those who completed the form stated they would be more confident in disclosing their status if they could be reassured that no one else in the practice besides their GP could access this information about their HIV status; however 10% stated that this would not dispel their concern.

Conclusion: This survey confirms that a continued high percentage of our HIV patients' GPs are involved in their care. However, despite concerted efforts, there remains a concerning proportion of patients who are reluctant to disclose their status to their GP and have ongoing concerns relating to confidentiality. Enhanced collaboration between patients, GPs and HIV centres in the form of working groups and patient forums could address these concerns.

Abstract P16

The TRxCare™ adherence support system: a pilot study of its acceptability to patients on virologically successful HAART

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Background: Adherence is key to the success of HAART, but there is little evidence that simple interventions can help. The TRxCare™ system is a pillbox that sends a mobile 'phone signal to a remote server when opened. It monitors dose events & texts reminders for missed doses & positive feedback on adherence. We assessed its acceptability in a pilot study.

Methods: Eligible patients had been stable on HAART for at least 90 days with a last HIV viral load <50 copies/ml and could read English. Subjects consented to use the modified pill-box for all their doses for the 24 week study. From weeks 13–24 only, text reminders were sent to the subject's own mobile 'phone if a dose was late; weekly text messages were sent to reinforce adherent behaviour. At weeks 12 & 24 subjects received verbal feedback on their adherence from the study team using data held on the system's server. Subjects completed an adherence questionnaire at baseline, 12 & 24 weeks. At 12 & 24 weeks they also completed questionnaires on the acceptability of the system.

Results: Fourteen patients participated in the pilot; all were male, median age 43 years (IQR 37–46); 11 were on once daily medication, 3 twice daily. At baseline reported adherence over the previous month was high at 99.5% & remained at 98% at week 24. The median number of reminders per patient was 14 (range 1–43). Dose times were later after reminders were switched on ($p=0.017$), but overall the number of doses missed was low (4.8% wk 0–12; 6.3% wk 13–24) & did not change over time. On days when a dose was taken, 81% of doses were taken within 1 hour of the correct time in both phases. At week 24 64% were satisfied with the system but 36% were neither satisfied nor dissatisfied. 50% found the text reminders & overall system useful & 67% found the verbal feedback useful. However 54% found the pill -box inconvenient or that it made more difficult to take HAART regularly; 55% found reminders irritating.

Conclusion: This pilot found remarkably high, consistent adherence in patients on stable HAART. While open to possible bias towards those willing to be monitored, this suggests that future UK studies of adherence interventions may need to select patients at risk of low adherence e.g. based on virological failure. However given that even in this highly adherent group, TRxCare™ presented some barriers to adherence further study is required before it can be generally recommended. Adherence interventions should address individual needs.

Abstract P17

Questionnaire-based evaluation of the contraceptive needs of HIV positive women at a south London HIV clinic

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Background: 331 HIV positive patients attend our service, of whom 557 (42%) are women. This study aimed to evaluate their contraceptive needs.

Methods: Questionnaires were distributed to HIV positive women >16 years presenting between 01.08.10–31.01.11. Data regarding age, ethnicity, HIV status, sexual activity, pregnancy history and contraceptive use were obtained. Data were analysed with Microsoft Excel 2007.

Results: 165 questionnaires were distributed; 109 were completed (response rate 66%). 61/97 (63%) women were of childbearing age (16–45 years) and 79% Black African. Median time since HIV diagnosis was 5–9 years. 67/97 (69%) reported contraceptive use: 51 (76%) condoms, 13 (19%) intrauterine device or system, 4 (6%) depo provera and 3 (4%) the oral contraceptive pill (OCP). Although 89/99 (90%) were taking antiretrovirals (ARVs), 29 (33%) women were unaware of potential interactions with certain methods of contraception. 3 women on ARVs were on the OCP; 2 of these prescribed by their GP. For those using condoms, only 32/51 (63%) reported consistent use. Contraception was accessed as follows: 32/51 (63%) during their HIV appointment, 11/51 'non-prescription' access, 6/51 GP, 5/51 family planning service at our clinic, 3/51 family planning clinic elsewhere and 2/51 young person's clinic. 77/102 (75%) had previously been pregnant and 36/91 (40%) reported unplanned pregnancies, with 18/36 citing the cause as 'no contraception used', 11/36 a 'failure of contraception', 2/36 cited both. 62 women reported pregnancies not ending in a live birth; 55% had terminations, 34% miscarriages and 11% still births. Frequency of contraceptive discussions varied: 30/77 (39%) had contraception discussed with them £ once a year, including 2 women who had never discussed contraception, 19/77 (25%) > once a year and 28/77 (36%) discussed it on every visit. 50/74 (67%) women discussed contraception with a doctor, often in conjunction with another healthcare professional. 57/76 (75%) of respondents stated preferring to access contraception at the same time as their HIV appointment; reasons included a wish to deal with issues in one appointment and a reluctance to disclose HIV status to other services.

Conclusion: An on-site service providing HIV positive women with effective, regular access to contraceptive information and prescription may increase appropriate contraceptive use, reducing the number of unplanned pregnancies and terminations.

Abstract P18

Following up persons 'lost to follow up': experiences of a medium-sized HIV centre

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Background: On average, 90% of adults attending HIV services in any one year attended the following year. The remainder become 'lost to follow up.' Some seek care elsewhere; others disengage from services and re-present late. We aimed to determine the rates of loss to follow up in our clinic population, and to identify subsequent presentation in alternative settings.

Methods: The hospital database was used to identify individuals who had not engaged in HIV care for more than 12 months during the period 2007–2010. Demographics, laboratory results and ARV experience at the last clinic visit were recorded. Medical records were reviewed to identify reasons for default. Where reasons were unclear, efforts were made to contact patients via telephone and by post. Finally, the HPA SOPHID database was interrogated to identify individuals who may have later presented for care elsewhere.

Results: Of 690 regular clinic attendees, 79 individuals (11%) were identified as being lost to follow-up. Of these, the majority (91%) were men. Three individuals (3.8%) had died, and 34 (43%) had formally transferred their care or returned to their countries of origin. For the remaining 42 individuals (53%) no documentation was available to explain why they had defaulted follow-up. In 7 cases (17%) there was evidence of attempted recall by clinicians. Following attempts to trace these individuals, two re-engaged in care. Attempts were limited by a lack of current contact information. Of the 40 truly lost to follow up (5.8% of total clinic caseload), the majority (70%) identified as white (with 20% identifying as black African). At the time of last visit, median CD4 count was 432 cells/l (range 7–823), and 18 patients (45%) were on antiretroviral therapy with 13 (72% of this group) having an undetectable viral load. The HPA SOPHID database revealed that three (7.5%) of these individuals have subsequently presented for care at alternative centres.

Conclusion: In our centre, a small fraction of attendees become lost to follow up. In fewer than half of cases, however, are reasons known. Attempts at recalling those patients truly lost were hampered by a lack of contact details. The use of the SOPHID dataset can be successfully employed to identify those still engaged in care in the UK. Maintaining contact details and improving communication with other healthcare providers (eg: primary care) may improve recall exercises in the future.

Abstract P19

Meeting the psychological needs of people living with HIV: an evaluation of the HIV psychiatric liaison service in an urban area

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Background: In response to recent guidelines regarding psychological support for people living with HIV, the aim of the study was to evaluate current HIV psychiatric liaison service provision in an urban area.

Methods: A questionnaire-based psychiatric liaison service evaluation was conducted, supplemented with a qualitative study focussing on the psychological implications and individual experiences of people living with HIV. Questionnaires were distributed to all HIV positive patients seen in clinic between 13th October and 8th December 2011 who were current or previous users of the HIV psychiatric liaison service. Quantitative data from the questionnaires was collated and represented graphically. Qualitative data from free text boxes was classified into themes. Following this, semi-structured interviews were conducted with 20 HIV positive patients attending Consultant, Registrar or multidisciplinary team clinics between 14th and 23rd November 2011. Interviews focussed on experiences of general practitioner (GP) disclosure, coping mechanisms and relationships with family, friends and partners. Qualitative data from the semi-structured interviews was analysed thematically.

Results: 18 questionnaires were returned over the study period (43% response rate) and none were excluded from the study. Patient satisfaction scores were high for all criteria with mean scores ranging from 3.2 to 3.5 on a scale of 1–4. 79% of respondents stated that they would prefer to discuss their mental health issues with the HIV psychiatric liaison team rather than their GP. Identified themes included the desire for specialised care, greater confidentiality and less stigma felt in the integrated sexual health setting. Disclosure rates were: 85% (GPs), 80% (friends), and 60% (family and partners). Complex adjustment experiences and coping mechanisms were identified. The majority of participants reported positive lifestyle changes and a proactive approach to the management of the condition. Less positive experiences included struggles relating to negative self-perception, denial and substance abuse.

Conclusion: Given the well documented links between HIV and psychiatric comorbidities, responsive and high-quality service provision is crucial. The HIV psychiatric liaison service has been shown to be a valuable provision for people living with HIV, however additional funding is essential to expand the service and further meet their psychological needs.

Abstract P20

HIV-positive female patients – are we offering effective methods of contraception?

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Background: Antiretroviral drugs have the potential to either decrease or increase the bioavailability of steroid hormones in hormonal contraceptives. If a woman on antiretroviral treatment decides to initiate or continue hormonal contraceptive use, the consistent use of condom is recommended. This is for both preventing Human Immunodeficiency Virus (HIV) transmission and to compensate for any possible reduction in the effectiveness of the hormonal contraceptive.

Objectives: An audit was carried out to review the adherence to the 2008 United Kingdom (UK) National guidelines for the management of the Sexual and Reproductive health of people living with HIV infection. According to the guidelines consistent condom use should be encouraged in conjunction with an additional contraception method.

Methodology: Retrospective analysis of 144 cases was undertaken to ascertain compliance of documentation of offer of contraception. All HIV positive female patients attending the department in 2010 aged less than 50 were included in the audit. 74 women were excluded from the audit. The exclusion criterion was currently pregnant, previous hysterectomy and no sexual partner in last 12 months. 23% were not sexually active in 2010.

Results: Majority of patients (66%) were black African and 52% were aged 36–50. Condoms were offered in 83% of cases and contraception was discussed in 51%. Out of 36 patients using Contraception, 33 were on Highly Active Antiretroviral Therapy (HAART). Out of 14 patients using hormonal contraception, 4 were consistently using condoms. Use of condoms was not documented in rest of 10 patients.

Conclusion: The recommendations were made to discuss drug interactions and consistent use of condoms with patients using hormonal method of contraception and HAART. This will help to prevent HIV transmission as well as unwanted pregnancies. As Genitourinary Medicine (GUM) services are moving towards integration with contraceptive services, priority should be given to HIV positive women to seek contraceptive advice in order to enhance their overall care.

Abstract P21

Establishment of an annual health clinic for HIV-positive individuals

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Background: BHIVA guidelines for the routine investigation & monitoring of adult HIV-1-infected individuals 2011 and EACS version 6 guidelines advise on appropriate annual monitoring which maintains the health of people living with HIV. Standard care at our centre aims to fulfil these recommendations, however, it is identified that patients frequently do not stay or are reluctant to take these opportunities when offered. With this in mind the multi-disciplinary team (MDT) discussed new ways of working in order to meet this need. The outcome of this was the establishment of a new annual health clinic (AHC).

Methods: The AHC was set up fortnightly & overseen by Clinical Nurse Specialists (CNS). Screening was performed for sexual health; urine protein/ creatinine ratio; urinalysis; cytology; Hepatitis B/C serology; cardiovascular risk (CVR); fracture risk; neurocognitive and mood screens. Disclosure, child testing & PEPSE are discussed with the patient. Findings are recorded in an easily identifiable booklet, filed in the notes for medical review at the doctor appointment 2 weeks later. Band 5 nurses co-ordinate the clinic & an MDT of Dieticians, Occupational Therapists, Sexual Health Nurses, & Health Advisors deliver the care. The appointment is approximately one hour. An information leaflet explained the purpose and format of the clinic i.e. it replaces a routine blood test appointment; it is not an additional visit. This one-stop shop enables other appointments throughout the year to be less time consuming & complicated.

Results: To date 99 patients have attended with 69% male, 31% female with a mean age of 42yrs. The satisfaction survey in progress suggests it is highly acceptable to patients. 100% have had CVR, bone fracture risk, neurocognitive & mood screening carried out. 100% have been offered a sexual health screen & of those 70% have been screened. A benefit is to proactively provide advice & screening to prevent common conditions occurring or detect them early. Patients have an opportunity to meet the wider MDT to develop therapeutic relationships.

Conclusion: The aim of the AHC was to ensure guidelines regarding annual patient care are met. The clinic has been instrumental in the identification of problems which may otherwise have gone undetected or taken longer to be recognised. This has allowed prompt treatment. An audit comparing AHC to standard care will be completed in March 2012.

Abstract P22

HIV-positive adolescents: bridging the gap between paediatric and adult HIV services

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Background: To characterise a cohort of HIV positive adolescents attending an outpatient transition service, for 18–24 year olds, at a SW London clinic.

Methods: A retrospective case notes review of all adolescents, currently or previously attending the transition service. Data was collected using a standardized database between 01/09/11–01/01/12 recording: demographics, HIV stage, anti-retroviral therapy (ART), psychosocial issues and sexual/ reproductive health data.

Results: 37 adolescents were identified. Median age 20, 19 (51%) male and 31 (87%) Black African. Most (97%) were vertically infected and 33 (89%) had transferred from paediatric services aged 18 years. 5 patients had already transferred to on-site adult HIV care, 3 had transferred elsewhere, 2 were lost to follow up and 2 had died. Of those vertically infected adolescents previously treated in paediatric services (n = 33), the median age at diagnosis was 5.5 years (range 1–16). The majority (79%) were symptomatic at diagnosis (CDC B/C). 27/33 (82%) had had an AIDS defining illness and 28/33 (85%) were taking ART; of whom, 15/ 28 (54%) had VL < 50c/ml. Median duration of ART was 11.5 years (range 2–20); only 4% were taking first line therapy. Side effects, simplification of the regimen and resistance (n = 7) were the commonest reasons for change. 43% self-reported poor adherence (2 or more missed doses over last 4 weeks). Most recent median CD4 count was 567 but in 20% was <200 cells/ll. 12 patients (33%) had missed ≥3 appointments in the preceding 12 months; none had been lost to follow up for >1 year. 9/33 (27%) had documented learning difficulties and 27% had mental health problems. Despite this 13/33 (45%) were undertaking university degrees. 21/33 (64%) report being sexually active, of whom 9 (43%) had a regular partner. Of those, 89% had disclosed their HIV status and 89% reported using barrier contraception. 38% of females had previously been pregnant and 25% had previously had a termination of pregnancy.

Conclusion: Characterisation of this cohort has highlighted the advanced stage of HIV at diagnosis, long duration of ART, high prevalence of side effects and poor ART adherence typical of this group. Encouragingly this vulnerable cohort, cared for in a dedicated service, displays a high level of educational attainment, and despite the frequency of missed appointments the service has maintained a high retention rate and low levels of loss to follow-up.

Abstract P23

The importance of social care support for people living with HIV: findings from a snapshot survey of healthcare professionals

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Background: Over the last two years there have been significant changes to the way in which social care for people living with HIV is funded. There is concern that the change from a ring-fenced grant (the AIDS Support Grant) to a non-ring fenced funding line in the Formula Grant for 'HIV/AIDS Support', combined with the wider Local Authority budget cuts, could threaten the provision of high-quality social care services for people living with HIV in England. As part of wider research into the importance of social care, we carried out a survey to find out what impact healthcare professionals working in HIV feel that social care support has on their patients' ability to manage their HIV and health more broadly.

Methods: In 2011 149 healthcare professionals working in HIV were surveyed to gather evidence on the value of HIV social care from a medical and public health perspective.

The survey was conducted online via Survey Monkey between 7 March and 15 April and was promoted to members of BHIVA, CHIVA, NHIVA and the Society of Sexual Health Advisors. The sample was opportunistic and is likely to overrepresent those with strong views on social care. Nevertheless the results offer an insight into the range of social care needs experienced by people living with HIV.

Results: Healthcare professionals frequently refer patients to social care services, the majority – 65% - referring at least once a month. The most frequently cited reasons for referrals were those associated with poverty. Psychological support needs were also frequently cited. The survey also showed significant number of patients had trouble accessing social care - 45% of respondents reported problems. Barriers cited included a lack of capacity in local services, high eligibility thresholds and the loss of specialised HIV social care support. However, the results also indicated that the vast majority of healthcare professionals – 77% - felt social care had a positive impact and helped their patients.

Conclusion: This survey illustrates the continuing need for social care support for people living with HIV, the positive impact that such support has on people's lives, and the value placed on it by HIV healthcare professionals.

Abstract P24

Improvement in time taken to see newly diagnosed HIV patients following implementation of five key measures

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Background: British Association of Sexual Health & HIV (BASHH) guidelines stipulate that all patients with a new HIV diagnosis should be seen by a specialist ideally within 48 hours or, at the latest 14 days of being informed of a positive result. Two quality improvement projects (QIPs) were done at a large teaching hospital during 2006–2010. Changes in service provision in the GUM/HIV department were made to attain this accessibility standard for new patients testing HIV-positive in the 2 GUM clinics and were evaluated again in 2012.

Method: The components of these 2 key QIPs over the 5-year period comprised: An increase in clinic frequency; the number of weekly new patient HIV specialist nurse clinics was increased from 5 to 11 facilitating more rapid reviews (2008)

Creation of new patient slots within every consultant and registrar led general HIV clinic in the HIV outpatient slot where previously there had been just been one HIV new patient clinic weekly (2008) Training health advisors (HAs) to use the trust appointment system which allowed them to give new patients nurses or doctors appointments (2009) Creation of a new HIV patient database which signposted health advisors and nurses to expedite appointments for new patients for medical review (2010) Establishment of a dedicated HIV seroconversion clinic to fast-track patients experiencing HIV seroconversion (2009) The benefits of these changes were evaluated in 2012.

Results: Mean time for new HIV patients to be offered an HIV nurse appointment fell from 31 days in 2006 to 7 days in 2011 (P < 0.001) and time to doctors appointment fell from 59 days in 2006 to just 12 days in 2011 (P < 0.001). 12/39 (31%) of patients were offered a doctor appointment within 48 h of receiving an initial positive result in 2011 versus 3/44 (6.8%) of patients in 2009 (P < 0.01). For nurse appointments; 18/27 (66.6%) were offered an appointment within 48 hours in 2011 versus 7/38 (18.4%) in 2009 (P < 0.001)

Conclusion: There has been a consistent decrease in the time to see a HIV specialist over 5 years. These changes have been embedded, resulting in sustained improvement. The majority (66%) of new patients are now being offered nurse appointments within 48 hours. In addition to more appointments, an important factor contributing to this improvement has been the enhanced multidisciplinary team approach; streamlining of the HA roles and nurse and HA database usage to expedite appointments for patients with greatest medical need.

Abstract P25

To determine the influence of a home delivery service of HIV medicines on adherence to HIV therapy

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Background: Successful treatment of HIV requires a high level of patient adherence to anti-retroviral therapy. Home delivery of HIV medicines has expanded rapidly over the last two year in HIV units in London and these stable patients are receiving supplies of four to 6 months. Evaluating whether change in the mode of supply of medicines is associated with any change in adherence and patient outcomes needs to be reviewed.

Methods: Retrospective analysis of medical notes of one hundred patients who were started on home delivery (HD) and 100 patients who received supplies from the clinic based hospital HIV pharmacy (standard care) over a 3 month period (Jan-Mar 2011) were reviewed over a 6 month period. Patient demographics and type of HIV regimen were recorded. HIV viral load, CD4 (%) and adherence were analysed using SPSS for windows version 18, McNemar test, repeat measure ANOVA test and independent t-tests.

Results: No significant difference was found in the number of patients with a suppressed HIV viral load who were on home delivery versus the standard care patients (P = 0.650). There was a general rise in CD4 (%) over time, but the average (mean) CD4 (%) was statistically similar between the two groups.

Adherence levels also remained statistically similar between home delivery and standard care patients (P = 0.350). Over 50% of patients on HAART did not have adherence recorded over the 6 month period.

Conclusion: The average (mean) HIV viral load and CD4 (%) was not significantly different between the home delivery and standard care group indicating that the mode of supply did not affect adherence. Adherence documentation needs to be standardized and documented routinely.

Abstract P26

Testing children of HIV-positive parents: how a look back review of living and deceased patients and an MDT approach can result in increased testing of children, teenagers and young adults

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Aims: (i) To perform a review of all current HIV positive patients attending HIV services in one city, to determine whether they have children and if so have they been tested for HIV.

(ii) To determine the feasibility of a look back exercise on deceased patients.

To use a multi-disciplinary forum to elicit the best approach to families with untested children.

Method: A review was performed of all current HIV positive patients attending the Departments of Genitourinary Medicine and Infectious Diseases, and those who had died. Where children were identified who had not had a documented HIV test performed in the UK, a discussion was held by a multidisciplinary team including the paediatric HIV team, specialised HIV social worker and specialised HIV nurses. Various approaches were used to encourage testing including GP IT systems.

Results: The look back exercise identified 309 families with children. For 274 families (89%) testing of the children had been completed. Of the 35 families, where testing was incomplete, 5 were refusing testing, 9 were awaiting paediatric appointments and for 21 either further clarification was required or discussion was on-going.

After the look back exercise, 8 families who still refused testing were referred to a bi-monthly MDT meeting. This has resulted in 6 children being tested where parents had completely refused previously, including where a mother had died some years previously and the family were not in contact with services. One child has legal proceedings underway and 6 further children remain untested. The approaches used, including the use of GP IT systems will be discussed. The on-going need, to ensure testing for those children who may subsequently enter the UK, was identified.

Conclusion: Testing children of parents who initially refuse can be achieved through the use of an intensive MDT approach, including where parents have died. However there will still be some cases where recourse to legal action through child protection services may be required.

Abstract P28

An audit of the clinical outcomes and user satisfaction of an HIV virtual advice clinic

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Background: Our regional HIV care network operates a monthly virtual clinic. This service has not been assessed previously as to the clinical outcomes from the advice it issues (audit), or as to physician (user) satisfaction with the process.

Methods: Cases presented at the meeting between June 2009 and September 2010 were retrospectively reviewed for clinical data (casenote review) and a clinician satisfaction questionnaire sent to the physician in charge of the patient's care. We used the following audit standards: 1) After a change in HIV therapy (or intervention) a patient should be virologically suppressed (HIV Viral Load <50 copies/mL) by 6 months. 2) Physician is satisfied with advice they receive (Likert scale rating of 3 or above, 1 = bad 5 = excellent).

Results: Twenty-five questionnaires were returned. Of those that took advice (n = 22), the mean Likert rating was 4.7 (range 5 to 4), in those that didn't take advice (n = 3) the mean Likert rating was 4.7 (range 5-3).

Advice Category (Number of advice episodes)	Took advice n (%)	If took advice, VL < 50 copies/ml at 6 months n (%) of those taking advice)	If took advice, Switched away from suggested regime by 6 months n (%) of those taking advice)	If took advice, Remaining on suggested regime 6 months after switch n (%) of those taking advice)
Viral load Rebound (18)	15 (83%)	6 (40%)	6 (40%)	9 (60%)
Drug-Drug Interaction (1)	1 (100%)	1 (100%)	0	1 (100%)
Co-Morbidities (8)	7 (87.5%)	7 (100%)	1 (14%)	6 (86%)
Previous cART treatment or resistance (10)	7 (70%)	4 (57%)	1 (14%)	6 (86%)
ARV side effects (10)	9 (90%)	8 (89%)	1 (11%)	8 (89%)
Total ARV advice episodes (47)	39 (83%)	26 (67%)	9 (23%)	30 (77%)

Conclusion: When advice was issued for patients with pre-existing resistance and cART treatment or viral load rebound, a higher than expected level of noncomplete HIV viral suppression at 6 months was seen. This potentially represents treatment compliance issues in a group of treatment experienced patients, as the aim of all advice issued was to achieve HIV viral suppression. Overall users of the meeting were satisfied with the process, even if clinical advice was not taken.

Abstract P27

Baseline HIV knowledge of adolescents: a retrospective review of intake knowledge assessments

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Background: Illness related knowledge is associated with treatment perceptions and understanding in chronic illness. The purpose of this study is to examine HIV specific knowledge of adolescents (aged 13-19) upon registration at a community organisation for people living with and affected by HIV in London.

Methods: During 2011, all new adolescent registrants at a community organisation undertook a brief, 5-item screening process to measure baseline understanding of key concepts related to HIV, including: basic comprehension of the HIV diagnosis, CD4 count, viral load, transmission routes, and ways for a person living with HIV to stay healthy. 66 new registration charts containing assessment were retrospectively reviewed to evaluate knowledge trends.

Results: 66 total charts were reviewed; 50 of 66 belonged to HIV positive (HIV+) adolescents and the remaining 16 belonged to HIV affected (HIV-Af) adolescents. Items were scored 1-3: scores of 1 indicated little or no understanding, 2 indicated some understanding, and 3 indicated a satisfactory understanding of basic concepts. Maximum score for individual assessment was 15 and minimum score was 5. The mean score for registrants was 9.136, indicating some understanding of key concepts related to HIV. HIV+ adolescents demonstrated a slightly higher overall understanding (mean 9.52) than HIV-Af adolescents (mean 8.563), a trend that was consistent across all items. There were no significant differences in knowledge between male or female scores. Adolescents aged 13 had lower mean scores than adolescents aged 14-19 (8.421 versus 9.511 respectively) Adolescents scored higher on broader concepts (HIV, transmission routes, and ways for a person living with HIV to stay healthy) than on specific concepts (CD4 count and viral load). Overall scores for understanding specific concepts were low both before and after adjusting for potential factors such as age, HIV status, or gender (mean of 1.712 for CD4 count and 1.5 for viral load out of a potential 3 points each item).

Conclusion: Adolescents demonstrated some understanding of basic concepts related to HIV however there is substantial potential for improvement, especially around knowledge of specific concepts like CD4 count and viral load. There is need for additional research to identify factors contributing to individual differences in HIV knowledge. Adolescents require targeted programming aimed at building HIV knowledge

Abstract P29

A national survey of HIV testing practices within intensive care units: a need to standardise patient care?A Pryce¹ and M Dodd²¹Royal Hallamshire Hospital, Sheffield, UK, ²Northern General Hospital, Sheffield, UK

Background: There is a national trend to increase HIV testing in myriad healthcare settings with little mention of Intensive Care Units (ICUs). It is unknown how intensive care units are guided in testing for HIV in England.

Methods: A national enquiry examining HIV testing in ICUs was developed in collaboration with the Intensive Care Society (ICS). 120 ICUs were contacted by email and asked to complete an online, pre-piloted questionnaire at a dedicated website. Data was collected from 1st August to 31st October 2011.

Results: A 44% (53/120) response rate was achieved. 5/53 (9%) ICUs reported having written guidelines for HIV testing. Four incorporated the UK National Guidelines for HIV testing (UKNG). One based testing upon specialist advice only. Ten units without written guidelines had discussed introducing them with three intending to do so within the next 12 months. Of the centres without written guidelines, 7/48 (15%) reported using the UKNGs to guide testing but a further 4/48 (8%) stated they only tested on specialist advice.

The 48 ICUs without written guidelines were given a list of 8 indicator illnesses and asked to state for which their units routinely tested for HIV. Eight gave no response. Three would not routinely test for HIV for any of the illnesses. Unexplained opportunistic infection was the most frequently tested (37/48; 77%). 27/48 (56%) routinely tested in the presence of pulmonary TB and 10/48 (21%) tested in the context of lymphoma. For each of the remaining indicator illnesses less than 10/48 (21%) ICUs routinely tested. No ICU performed HIV testing for all indicator illnesses listed.

Of the 7 units without formal written guidelines who were using UKNG as a basis for HIV testing, less than half reported a more than 25% testing compliance.

Qualitative data revealed some misinformed beliefs regarding HIV testing practices; perception of those 'at risk' of HIV infection and legislation for testing patients lacking mental capacity to consent.

Conclusion: Diverse HIV testing practices were observed across ICUs. The majority (91%) did not possess written guidelines for HIV testing. Some had discussed the need to introduce formal guidelines but only a minority had taken decisive action. Poor compliance with National Guidelines was widespread. This survey indicated a need for raising the profile of HIV testing nationally in ICUs. A consensus within the ICU community to standardise and increase appropriate testing will improve patient care.

Abstract P30

Financial Incentives and motivational interviewing for adolescents with advanced HIV disease; a pilot serviceC Foster¹, S McDonald¹, G Frize¹, J Walsh¹ and S Fidler²¹Imperial College NHS Healthcare Trust, London, UK, ²Imperial College London, London, UK

Background: In the UK financial incentives (FIs) have been widely used in adolescent populations; from the Educational Maintenance Allowance to improving uptake of Chlamydia screening. Emerging evidence suggests FIs improve medication adherence in select populations. A small proportion of adolescents with perinatally acquired HIV (PaHIV) transfer to adult services with longstanding poor adherence and advanced disease, despite intensive MDT support in paediatrics, resulting in deaths due to end stage HIV despite a treatable virus. We describe a single centre experience combining FIs with motivational interviewing (MI) to improve adherence.

Methods: The deaths of 2 young adults due to poor adherence, prompted MDT development of the 'Incentive scheme (IS)' in consultation with service users demonstrating both poor and excellent adherence. Eligible patients (CD4 count £ 200, off ART despite multiple attempts) received MI by psychologist/ CNS during clinic and gift vouchers dependent on VL of: £25 for each fall in VL at 2 and 4 wks, £50 VL < 50 c/ml, £25 VL < 50 at 3/12, 6/12 and £50 VL < 50 at 1yr. Maximum FI £200/patient. From Jan 2010, IS was open to all aged 16–25yrs with; PaHIV, longstanding poor adherence despite MDT support, CD4 £ 200 cell/ul, willing to start ART and to sign the patient agreement. IS was discussed with clinical and research ethics committees and designated a service intervention. IS was financed by donated MDT speaker fees and outcomes assessed by VL/CD4 count at 1yr.

Results: 11 young people enrolled, 1 declined. Median age 19 (range 16–23), 8 female. At start, median CD4 count 30 cells/ul (IQR 10–160), median VL 12,870 c/ml (IQR 2,382–26,300), previous ART regimens median 3 (range 2–9)

ART commenced: OD PI based (8), Atripla(1) BD darunavir/rvtv, raltegravir, etravirine (2), 7 known to be sexually active; 4 partners ever tested, all negative. Outcomes: 9/11 ever achieved VL < 50, 5 sustained at 1yr. Median CD4 count at 1yr 140 cells/ul (IQR 60–200). Clinical outcomes: No deaths, 2 new AIDS diagnoses (PCP), 6 required admission and 1 pregnancy (delivery VL < 50). Total FI expenditure £1,300; £76 per 50 CD4 cells at 1yr. Currently: median 6/12 post IS; CD4 160 (IQR 20–290), 5 VL < 50 c/ml.

Conclusion: Adolescents represent a particularly vulnerable group living with HIV and many struggle to overturn poor ART adherence set up in childhood. In our experience some young people die with treatable disease and novel adherence interventions are urgently needed.

Abstract P31

Predictors for delayed baseline assessment of newly diagnosed HIV-positive adults in the UK: variation across HIV diagnosis settings

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Background: To ensure optimal care after HIV diagnosis, BHIVA guidelines recommend baseline tests (CD4 counts and viral loads) are undertaken within two weeks of diagnosis. We use a national cohort of persons newly diagnosed with HIV to assess adherence to guidelines and examine predictors for delayed baseline assessment.

Methods: Adults (≥15 years) diagnosed with HIV in 2010 reported to the national HIV database were linked to the CD4 laboratory data. Each adult's first CD4 count was used as a proxy for the baseline assessment date. Adults were defined as having a 'delayed baseline assessment' if their first CD4 test was >1 month after diagnosis. Predictors for delayed baseline assessment including age, sex, ethnicity, exposure category, and facility of diagnosis (antenatal clinics, general practitioner (GP), STI clinics, other medical settings, community, prison, and blood transfusion services) were examined in a multivariate analysis.

Results: In 2010, 6,125 adults were newly-diagnosed with HIV in the UK, of whom 3.0% (184) died in a year (as reported to June 2011). Of those surviving, 4,023 (68%) had a CD4 test within two weeks, 79% (4,683) within a month, 10% (574) after a month and 11% (684) were likely not assessed by the end of 2010 (42% of those 684 adults were diagnosed in the first half year). Where facility of diagnosis was reported, 69% (2,836/4,126) of adults were diagnosed in STI clinics (77% of 2,784 men and 52% of 1,342 women). Other diagnosis facilities included GP (6.8% of men and 9.6% of women), other medical settings (14% of men and 17% of women) and non-medical settings (2.2% of men and 0.9% of women). One-fifth (282/1,342) of women were diagnosed in antenatal clinics. Of adults diagnosed in STI clinics, about one in ten were transferred to another specialised clinic for HIV care.

Predictors for delayed baseline assessment included: persons who inject drugs (PWID) (adjusted odd ratio (aOR) =2.78, 95%CI [1.52, 5.08], ref: men who have sex with men), adults diagnosed outside London (aOR=1.49, [1.18, 1.90], ref: London) and those diagnosed at a GP (aOR=2.77 [1.98, 3.88], ref: STI clinic) or other medical settings (aOR=1.82, [1.36, 2.45], ref: STI clinic).

Conclusion: In the UK four in five patients are rapidly assessed following diagnosis. Clinical audits and a review of local referral pathways should be conducted to ensure prompt assessment and integration into HIV care after diagnosis.

Abstract P32

Management of stable HIV patients in a community-based satellite outpatient HIV service: an appropriate model of care

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Background: The medical model of care for people living with HIV has changed over the past 30 years. Management has moved from an inpatient to an outpatient-based model, especially as the number of patients stable on treatment increases. The BHIVA guidance 'standards for HIV clinical care 2007' identified two distinct types of services required to meet the needs of HIV positive patients.

Firstly a HIV centre providing acute inpatient care and referral services for peripheral centers in networks and secondly HIV units providing outpatient care for the majority of patients with uncomplicated HIV infection. We aimed to evaluate this model of care in a North London community based satellite outpatient service against current best practice guidelines (BHIVA clinical standards 2007).

Methods: Data was collected retrospectively from electronic patient records and case notes. A pathology lab link was used to track if resistance tests were sent and for hepatitis serology. Data was collected and analyzed using excel.

Results: All HIV clinic attendances between 1/10/2010 to 31/12/2010 were included. This was a total of 106 patients. The average age was 40.6 years.

52% were male. The standards looked at were: (i) HIV testing & diagnosis: There were 14 new diagnoses with an average CD4 count of 540; two of the newly diagnosed had a CD4 < 200.

(ii) Initiation and use of HAART: 71% were on HAART. Of the newly diagnosed four did not have a resistance test at baseline. For those starting HAART for the first time 9.4% did not have hepatitis B status checked in the previous year.

Four had a CD4 count of <200 and of these only one was not on HAART.

(iii) Failure of HAART: 79.3% achieved an undetectable VL within 6 months of starting HAART. 86.6% of patients were fully suppressed on HAART. One failed a 1st line regimen and was changed to 2nd line.

(iv) Acute Illness: One patient was transferred for inpatient care.

(v) Sexual Health: 62.3% had an STI screen in the previous 12 months, 82% of women had cervical cytology.

(vi) Mortality: There were no recorded deaths, 3 patients were lost to follow up.

Conclusion: Our findings suggest that management in a community based satellite HIV centre is in line with best practice guidelines, with an increasing trend in no of diagnoses, good average CD4 count at diagnosis and few with CD4 < 200. HAART was used as per guidelines and sexual health screening was adequate. This supports the management of stable patients in satellite centers.

Abstract P33

HIV testing in cancer: experience from a tertiary oncology hospital

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Background: HIV infection has been shown to increase the risk of malignancy. Non-Hodgkin's lymphoma, Kaposi's sarcoma and cervical cancer, in particular, are AIDS-defining conditions. Patients with these conditions should be routinely recommended to have an HIV test. The UK chief medical officer, in a letter in September 2007, emphasised increasing the detection and diagnosis of HIV.

Methods: Case notes and laboratory virology results of patients referred or initially diagnosed with Non-Hodgkin's lymphoma (NHL), Kaposi's sarcoma (KS) and cervical cancer from March 2007 to July 2011 were retrospectively reviewed.

Results: 1391 patients were diagnosed or referred with NHL, KS or cervical cancer within the study period. A sample of 229 case notes and laboratory evidence of testing were reviewed. Twenty one percent (34 of 158) patients with NHL were known to be tested for HIV; eighty-six percent (6 of 7) patients with KS were known to be tested for HIV; and one percent (1 of 64) patients with cervical cancer were known to be tested for HIV.

Conclusion: A significant number of patients presenting with HIV clinical indicators to this tertiary oncology hospital are not being offered a HIV test routinely. This represents a missed opportunity and increases the potential for late diagnosis and onward transmission of HIV. The lymphoma unit are in the process of incorporating universal testing for all new diagnoses and referrals.

A multidisciplinary team has been organised to negotiate testing within the colposcopy services in the region.

Abstract P34

HIV-positive adolescents: characteristics and treatment challenges

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Background: To characterise the population of HIV positive adolescents attending outpatient HIV services at a district general hospital in South London. At the time of study, there were no dedicated adolescent services within the department, the study was conducted to identify patient needs and inform service provision.

Methods: A retrospective case note review of all HIV positive patients aged 16–25.

Results: 46 patients were identified. Median age 23, 70% (32/46) were female and 52% (24/46) were of Black African origin. The most common HIV risk factor was unprotected heterosexual intercourse (57%). 10 patients (22%) were vertically infected and had been transitioned from paediatric services. 18 (39%) of the adolescents had lost either one or both of their parents. There was a high incidence of self-reported alcohol misuse (21 of 36), recreational drug use (10 of 37), mental health problems (18 of 41) and attempted suicide (6 of 46). 42% of patients were sexually active in the last 6 months, of whom 30% had a regular partner. Of those with a regular partner, 82% had disclosed their status but only 55% reported using

Characteristic	Number (%)
Currently on HAART	13 (48)
NNRTI	14 (52)
PI	27
Median (range)	15 (2–78)
Length of time on treatment (months) n=27	10 (37)
CD4 count on Rx (n=27)	17 (63)
<350	16 (70)
>350	2 (9)
Adherence (n=23)	5 (21)
Excellent	9 (20)
Good	25 (56)
Poor	11 (24)
DNA in last 12 months (n=45)	
0	
1–3	
>3	

This patient cohort had advanced disease - 57% (26) of patients had CDC stage C disease. 59% of patients were currently on HAART therapy (table 1) and for 70% (19) this was their second regimen. Those patients who had transitioned from paediatric services were more likely to be symptomatic at diagnosis (50% vs 14% P = 0.014), been exposed to multiple regimens (100% vs. 60% P = 0.046), have poor adherence (71% vs. 0% P = 0.07 x 10⁻⁶) and also more advanced disease (CDC stage C) (80% vs 44% P = 0.06) compared to the behaviourally infected young people.

Conclusion: This study highlights the high prevalence of psychosocial problems and complex medical needs amongst HIV positive adolescents.

Patients who had transitioned from paediatric services had additional complexities. The endorsement of multidisciplinary 'one-stop' clinics providing HIV care, sexual and reproductive health and psychological support in a single visit may address some of the poor prognostic factors characteristic of this cohort.

Abstract P35

HIV and parenthood: clinicians and commissioners working together to make this a reality for our patients

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Background: In the past patients with HIV requiring sperm washing or fertility treatment often needed to travel long distances as such treatments were available only in one centre in the UK. In the absence of any clear referral pathways managing such patients proved extremely challenging to clinicians. Patients experienced long delays and significant inconvenience during this stressful period. With the development of additional centres offering such treatment we worked with colleagues in the Sexual Health Network and local PCTs to design clinical and commissioning guidelines and referral pathways for these couples. We audit how these guidelines have been implemented since their introduction and since the setting up of dedicated HIV fertility (complex) clinics in 2010. **Methods:** Retrospective case note review of all patients entered into the fertility database set up at the time of adoption of above guidelines in June 2010. Data including demographics, clinical characteristics and pathway referral times were collected.

Results: A total of 28 couples were reviewed between June 2010 and December 2011, in 12 of these both partners had HIV and in the other 16 only one (discordant) had HIV. Of all 56 patients a total of 17 women (average age 32 years) and 23 men (average age 36 years) were HIV positive. The majority of the couples attended for reproductive advice and with fertility problems but in at least 11 couples, sperm washing was also warranted to prevent transmission of HIV from a positive male partner to a negative female. The pathway of referrals were from standard HIV clinics to complex clinic (average time 82 days) then onto local gynaecology team for a decision regarding need for fertility treatment (average time 148 days). A specially designed form was then completed and submitted to the commissioning panel (average time to decision 47 days) and then an onward referral to the specialist fertility treatment centre (average time to review 61 days).

Conclusion: Even with our limited experience we feel that these guidelines and the subsequent introduction of fertility clinics have streamlined the previously complicated and haphazard referral process for couples where one or both partners might have HIV and who wish to start a family. During the process of writing up and subsequently putting these guidelines into practice clinicians from different specialities and commissioners have successfully worked together towards achieving a common goal.

Abstract P36

Contraceptive preferences following pregnancy among HIV-infected women: a study from a district general hospital in the UK

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Background: Safe and effective family planning practices are important among sexually active HIV infected women in reducing HIV transmission and to avoid unintended pregnancies. Concentrations of hormonal contraceptives can be altered when co administered with anti retroviral therapy (ART) and interactions are not always predictable.

The objective of this study was to determine patterns of contraceptive utilization among HIV positive women following a pregnancy.

Methods: It is a retrospective case notes review of all the women who had a pregnancy during the period of 2008–2011. A total of 87 women were included in the study. Data were collected from Genitourinary Medicine records using a structured questionnaire and analysed by using SPSS program.

Results: Mean age was 34 yrs ranging from 20–43 yrs. About a half were married (47) and a quarter (23%) were single and 87% sexually active.

Majority (91%) were of African origin; 67% had HIV subtype C; 26% resistant to one or more class of HIV drugs; 55% had a nadir CD4 fewer than 350; 44% diagnosed at an antenatal setting and 71% were living with HIV for more than a year. Of the partners, 38% have HIV and 73% were aware of their partner's HIV status.

In the past, 18% had a miscarriage and 16% reported a termination of pregnancy. Consistent condom use was reported as 18% and 7% never used a condom; two thirds of women are on ARTs. In 27% of women, the last pregnancy was not planned and 7% has a positive child.

Condoms were the most popular single method of contraception (49%) followed by Depo-Provera (14%), sub dermal implant (10%), combined oral contraceptives (8%), progesterone only method (4%) and tubal ligation (4%).

Intrauterine devices were the least popular method used by 1% of women and 8% was not using any form of contraception.

Discussion: Patients taking concomitant hormonal contraceptive and antiretrovirals are counseled to use an alternate method of birth control in addition to the hormonal agent. Despite changes in hormone concentrations, there are limited data on the effects of antiretroviral drugs when combined with hormonal contraceptives.

Conclusion: While condoms are the most popular method, Depo-Provera and Implant remain the preferred choice of hormonal contraceptive method among women after a pregnancy. Clear guidelines are needed as to the interaction between the ARTs and hormonal methods in order to prescribe them safely.

Abstract P37

The impact of courses for people with HIV on their knowledge, health and behaviourK Alexander¹ and C Armstead²¹George House Trust, Manchester, UK, ²Elton John AIDS Foundation, London, UK

Background: To assess the impact of its courses for people with HIV, funded by the Elton John AIDS Foundation (EJAF) George House Trust (GHT) operates a monitoring system based on the completion by clients of questionnaires at key stages.

Methods: Clients taking part in a GHT course for people newly diagnosed with HIV or a residential weekend for people living with HIV, were asked to complete a questionnaire at three key stages: before the course; at a recall meeting 5 to 6 weeks after the course and 12 months after the course. The questionnaires at each stage asked the same questions focusing on 3 broad areas: knowledge and understanding of HIV (for the newly diagnosed course only); emotional and physical health (including engagement with health services); sexual behaviour and substance use. The response rate for the recall questionnaires was 61% For the 12 month questionnaires, the response was 7%. Therefore, the results reported refer only to participants who completed an initial and recall questionnaire for the courses they attended. A focus group and 18 in-depth telephone interviews with course participants supplemented the questionnaire data.

Results: The newly diagnosed courses considerably increased participants' understanding of HIV. For example, there was an increase from 29 to 69 in the number of people who said they understood fully what CD4 count means.

While participants reported little change in their physical health, the courses gave them greater confidence in dealing with clinical staff and provided some with strategies to make their relationships with clinicians more productive.

The courses had a generally positive effect on participants' emotional health with respondents reporting less depression, improved self-esteem, greater self-confidence and reduced isolation. The results on sexual behaviour and substance misuse were more mixed, but there was evidence of increased thinking around disclosure and condom use. The courses also provided people with an opportunity to reflect on their substance use and information to support efforts to change behaviour.

Conclusion: GHT's courses are effective in increasing participants' knowledge of HIV. They also contribute to reduced isolation and improved emotional health among participants, and provide a forum for increasing thinking and discussion of sexual behaviour and substance misuse.

Abstract P38

A retrospective study of HIV testing in intensive care: significant numbers meet testing criteria according to national testing guidelinesM Dodd¹, P Collins², D Dockrell² and C Scott¹¹Intensive Care Medicine, Northern General Hospital, Sheffield, UK, ²Department of Infection and Immunity, University of Sheffield and Royal Hallamshire Hospital, Sheffield, UK

Background: HIV may first present as critical illness requiring general intensive care (GICU) management. Early recognition of HIV in such patients is key to their optimal management. However, in a recent national survey a majority of GICUs did not use any guidelines for HIV testing. The UK National Guidelines (UKNGs) were developed to improve early detection of HIV infected individuals, particularly when presenting with other illness. Testing is typically offered to patients with mental capacity to consent. In GICUs, testing rates may be low because of concerns over patients lacking capacity and nonadoption of formal testing guidelines. Adoption of UKNGs within this setting may help to raise HIV testing rates in line with national trends. This large cohort study assessed all GICU admissions for HIV testing using the UKNG criteria.

Methods: Over one calendar year all admissions to 2 GICUs within the same NHS Trust were retrospectively assessed against the UKNG criteria for HIV testing. 2 assessors (critical care registrar and infectious diseases registrar) reviewed the electronic records and independently placed patients into 3 study groups: 'Y' met UKNG criteria for HIV testing, 'N' did not and 'P' did not meet criteria but had a clinical picture that warranted testing on clinical suspicion.

Following this strict application of the criteria, a further analysis was undertaken using a pragmatic approach to the UKNG: those where testing could reasonably be delayed until the post ICU period or where a strong alternative factor had led to the indicator illness (e.g. post operative, hospital acquired pneumonia) were excluded. When assessors' decisions differed, an adjudicator (HIV consultant) was asked to give a final decision on testing.

Results: Without the use of HIV testing guidelines, 4% of admissions were tested for HIV. With strict retrospective application of UKNGs 320 (30%) of GICU patients should have been tested for HIV. Using the pragmatic application of the UKNG 186 (18%) still would have been tested.

Conclusion: In the absence of formal guidelines in these GICUs HIV testing rates were low. A pragmatic application of the UKNG would lead to a fourfold increase in testing. Strict application of the guidance would result in a greater than seven fold increase. Although UKNGs are not specific to the critical care environment the adoption by GICUs in their present form is sufficient to markedly increase appropriate HIV testing rates.

Abstract P39

The economic hardship faced by families and children affected by HIV in the UKP Bravo¹ and P Harrowing²¹Children With AIDS Charity, London, UK²Department of Primary Care and Public Health, Cardiff University, Cardiff, UK

Background: People living with HIV (PLHIV) are facing a long-term condition. Improvements in life expectancy have helped people to reframe their lives and many of them are deciding to make families and have children. Although parenthood has been identified as a positive process for PLHIV, HIV-affected families are facing difficulties to maintain economic stability and cover basic needs of their children. Fears of stigma and discrimination are still being described as one of the main reasons PLHIV do not seek help and support. As part of the only UK-wide fund, which provides financial support to families affected by HIV, this research aims to describe the social and economic needs of children affected by HIV.

Methods: Data was collected from application forms submitted to the fund from January 2010 to December 2011. Support workers completed the applications in collaboration with the families. Data retrieved was the weekly income, household structure, number of children within the family and the main need of the family/children by the time of the application. A descriptive analysis was conducted.

Results: During a period of 24 months a total of 1,065 applications were received and analysed. Over 1,700 children affected by HIV benefited from the fund. 80% of the children were living with only one parent. Most of the families have insecure immigration status and parents were not entitled to work in many cases. Parents were unable to cover basic needs of their children such as clothing, school items and living expenses. Interesting an increasing number of HIV-positive women who were expecting a new baby were in need of support to provide formula milk to their new child.

Conclusion: Children affected by HIV and their families are facing a difficult economic and social scenario. Families are unable to provide basic items to the children, which can make it harder to cope with other dimensions of HIV such as social isolation and fears of discrimination. Lacking clothing, basic items or food brings new worries and stressors to the family and the children. This research supports the call for further funding available to families living with HIV, as well as the need to systematically explore how the lack of economic stability is affecting the coping strategies children and family are using to overcome their HIV-affected condition.

Communication theory

Patient participation comes of age

Juliet Bennett

Freelance Nurse Advisor

History and background

In western societies the relationship between medical clinician and patient has traditionally been one where the patient is a passive recipient of advice and treatment from medical 'experts'. One could argue that the success of medical science has brought about a role of passivity on the part of the 'lay public'. This in turn has boosted the self-image of healthcare professionals and perpetuated their sense of power. It may explain why historically many people with chronic illness did not acquire the skills or knowledge to manage their own disease. People appear to have assumed less and less responsibility for what happens to their bodies and their minds [1].

In his 1975 book *Medical Nemesis* [2] Illich argued that clinician authority had been so over-extended that the nature of modern medicine itself became a threat to health. Although the 'medical model', in which the healthcare professionals diagnose and prescribe and the patient complies, had for a time appeared to work reasonably for acute conditions, it became more apparent in recent decades that this approach was far less effective with chronic illness. A visionary Illich suggested that the ill effects of 'medicalisation' might be reversed if the historically 'passive public' were to recover its 'will to self-care'.

In the 1980 and 1990s access to a vastly expanded array of health information, largely as a result of internet technology, along with an upsurge of interest in alternative therapies, appears to have fuelled this new 'will'. Patient activists in the USA

and Europe began to assert their claims to be seen as experts in their own illnesses and to play a more active part in healthcare decision-making. From legalisation on termination of pregnancy and access to contraception, to bills of patient rights and living wills – a significant rise in both patient choices and patient safeguards has been seen in the arena of healthcare in recent decades.

Improvements in technology, together with increasing longevity and life expectancy, are making medical interventions and treatments more appropriate and applicable for greater numbers, especially older people. The concept of the health service as a marketplace, and the associated shift from producer-led to consumer-led services, has also influenced patients, now armed with knowledge and skills to challenge professional dominance and power.

However, we can also argue that growing demands for cost containment and market discipline has limited the autonomy of both clinicians and patients – with the educated, articulate and affluent benefiting conspicuously from this marketplace NHS, while the vulnerable and marginalised struggle for recognition and support in becoming partners in decision making.

The public health model

The public health model of the 1980s and 1990s appears to have been ineffective in stopping the increase of chronic conditions related to the ageing of our populations [3], and there is also little evidence that this approach was effective in preventing HIV transmission in the United Kingdom. Sigma Research [4], for example, reported a far greater frequency of unprotected sexual intercourse with both regular and casual partners among men who had sex with men in 2000, compared to in 1995; while NICE [5] in 2003 found no review-level evidence of cost efficacy, or that social-political interventions had been effective in addressing inequalities.

It would be easy to oversimplify the search for an explanation. Blaming the lay public is a common response, with the lay person being labelled as ignorant and/or irrational. (Typical criticisms from clinicians would probably include refusal to believe the 'evidence' arising from scientific research; complaints about paying for healthcare, the quest for unsuitable services such as cosmetic surgery –



Clinician authority: over-extended?

and a disregard for the sensible advice given them to stop smoking, drink less and exercise more!)

Today's public health model continues to focus on determinants of health across a population, broadening the focus from individual behaviours and risk factors to population-level issues such as inequality, poverty, and education. This approach also advocates population-based policies that seek to improve health in an equitable manner. Furthermore, attempts have been made to improve the management of selected chronic conditions through the introduction of national service frameworks together with the associated activity of the NHS Modernisation Agency.

Partnership models

For many years government policy focused on improving access to elective care, but different models have become necessary because chronic conditions now predominate over acute illnesses in the United Kingdom and other industrialised countries. Patient-centred care, partnership working, collaboration, self-care and patient empowerment are terms used to reflect some of these new ways of working. Several authors make a distinction between patient collaboration and patients' ability to undertake self-care.

- Patient collaboration is seen as facilitated during a consultation. Whether it is called 'collaborative care' [6] or 'patient-centred care' [6], it is an approach where providers work with patients to set and attain shared goals and negotiate decisions regarding treatment and care.
- 'Self-management' or 'self-care' can be defined as the activities a patient undertakes on their own initiative to control the symptoms and progression of their condition.

Potential threats and challenges

Working with patients as partners is not straightforward. In some contexts one or both parties can feel threatened by the other, and there are various other significant challenges, all of which must be recognised.

- Cost implications: the ethics of care and economics of care cannot be separated. Chronic disease represents a huge burden of ill health in the UK and a large cost to the NHS. All initiatives need to take into account these limited and already over stretched resources.
- Tensions arise when professional opinion is challenged.
- Clinicians' agendas often differ from those of patients.
- An 'expert patient' can exemplify and promote health inequalities, should this role be taken by a patient of a relatively privileged background who is well educated and articulate.

- Variability of patients' skills, willingness, ability, for this role demands great flexibility from clinicians and care models – and perpetuates health inequality, see above.
- The basis for patient views and experiences may be seen by professionals as 'anecdote': should this input be given the same credibility as the evidence-based view?

Patient empowerment

Approaches to healthcare provision, where patients are active decision-makers in issues related to their own care, is termed 'empowerment'. This has been defined as the 'process of increasing personal, interpersonal, or political power so that individuals can take action to improve their situations' [7]. The action taken is designed to effect change in an active, outwardly focused manner. It is important to remember that empowerment is not a final destination, where a patient eventually arrives; it is an ongoing process that involves growth and change over life's course.

Another important aspect of empowerment is that it 'suggests emancipation from something' [8]. For individuals living with HIV/AIDS, this 'something' could be the initial perception that there is little they can do to influence the quality or duration of their lives. In this instance, empowerment returns to the individual a sense of self-determination. In one study [9] of HIV/AIDS 'long-term survivors', the ability to 'make choices' was identified as one of six characteristics of this group. Making choices involved learning how to take control of one's life and was an action clearly linked to empowerment. Specifically noted was that 'empowered members assume a more collaborative decision-making role with their physicians'.

'Self-management has become central for conditions such as asthma, heart disease, HIV and diabetes.'

A further interesting and relevant study [10] set out to investigate how patient empowerment affects the traditional medical relationship between patients with HIV/AIDS and their physicians. Three themes emerged to reveal that patient empowerment (a) situates responsibility with the patient; (b) redefines patients' perceptions and expectations of their physicians; and (c) promotes a partnership approach to healthcare. In summary, the findings of this study revealed that patient empowerment affects the traditional physician-patient relationship in positive ways that enhance communication and collaboration and may lead to better health outcomes as well.

Self-management

Patient self-management has become central for long-term conditions such as asthma, heart disease, HIV and diabetes. There is increasing acknowledgement amongst professionals that it is people with chronic disease who have the most comprehensive expertise in dealing with their own condition. The Department of Health has reflected this understanding in many papers and initiatives. In the field of HIV, the standards from MedFASH NHS HIV services [11] list at Standard 3 the need to facilitate the empowerment of people with HIV to have personal control and choice over the management of their HIV. Joint decision-making, and recognising stigma and social exclusion unique to HIV disease, are given priority.

In the United States, the 'Chronic Care Model' has been positively evaluated and deemed successful. A key component here is the support of self-management. A report by the Institute of Medicine (IOM) in the US defines this as 'the systematic provision of education and supportive interventions by health care staff to increase patients' skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting and problem-solving support' [12].

Evaluations of self-management programmes have shown significant benefits including:

- a marked drop in demand for services such as GP consultations, outpatient visits, A&E services;
- improved cognitive symptom management, better communication with physicians, enhanced self-reported general health;
- reduced health distress, fatigue, disability, and limitations to social/role activities.

The participants of one study spent fewer days in the hospital, and there was also a trend toward fewer outpatient visits and hospitalisations [3]. However, not every chronic patient becomes an expert in their disease and not everyone manages their disease in a way that enhances wellbeing.

The expert patient

In 2001, after evaluating many small-scale self-management programmes, the NHS started implementing a nationwide self-management programme called the Expert Patients Programme [13]. The content was derived from patients' knowledge about their own medical conditions, as well as their insight about living long term with a disease. Such programmes use these experienced lay people as mentors for others living with the same condition.

The 'Expert Patient' is defined by the Department of Health as one who:

- understands that the quality of their life is

primarily up to them;

- believes that they can exert significant control over their own life;
- is determined to live a healthy life despite their chronic condition;
- is realistic about the impact of their disease;
- has worked out what services exist and how they can be accessed.

An evaluation of the Expert Patients Programme was undertaken by the National Primary Care Research and Development Centre on behalf of the Department of Health in 2004. The final report, published in December 2006, was not able to reach a conclusion on the extent to which the programme had been effective; however, it did find that people benefited from self-management education, not only by improving their knowledge but also through sharing their experiences and learning with and from other people in similar situations [14].

Conclusion

As we have seen, facilitating self-managed care and empowerment is no easy task and implementing these models presents significant challenges, both to healthcare professionals and service-users alike. Particularly pertinent to the HIV population are the challenges these models present in terms of how best to reach society's most at-risk and vulnerable groups. In addition, all healthcare professionals have limited resources, and not all patients are able or willing to become 'empowered'.

Chronic disease accounts for the majority of disease burden in the UK and Europe, and it certainly looks as if our health systems will only be able to cope with this increased demand on resources through adopting such models. Although these should not, and never can, replace professional acute care, learning to self-manage can give those with chronic diseases the skills and confidence to recognise significant symptoms, manage medication, decide which treatment is most suitable for them and make the best use of available services.

Such developments are welcomed by the Editorial Board of *The Lancet*, who

'... doctors should get down from their pedestals, but patients must get up from their knees'

— Robert Johnstone, International Alliance of Patients' Organizations

comment that, 'empowerment is a process for the individual and all those who might advocate for it. Of all the challenges ahead, starting and continuing a dialogue directly with medical professionals on patient empowerment is a critical step' [15]. Noted also was a remark by Robert Johnstone of the International Alliance of Patients' Organizations [16], an insightful and amusing reflection on the progress still to be made: 'doctors should get down from their pedestals, but patients must get up from their knees'.

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HIV NURSING

CARING FOR PEOPLE AFFECTED BY HIV

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