HIV and homelessness in central London: Reflections from a specialist homeless general practice

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Disclaimer

Some details of cases have been changed in order to avoid patient identification. They remain representative of presentations to the practice.

What do we mean by homelessness?

Homelessness is highly complex; there is a wide range of reasons why people become and remain homeless, and it is well beyond the scope of this article to attempt to discuss it in detail. The term 'homelessness' is interpreted in a variety of ways, depending on perspective and context. The definition which is generally accepted within healthcare settings includes rough sleepers and those in temporary accommodation such as hostel dwellers, couch surfers and squatters [1].

Health implications of homelessness

Homeless people face a 'tri-morbidity' of health problems: substance misuse, physical health and mental health problems [2]. There is a growing body of evidence showing the increasing economic costs and health impacts of this phenomenon. Homeless people cost, on average, four times more than the general population in healthcare terms, attend urgent care many times more frequently, spend eight times longer in hospital, and die much younger. One-in-fifty homeless people have TB – 25 times the national average [3]. Only one in three are registered with a GP [3].

The service the author works in

Great Chapel Street Medical Centre has been providing services to homeless people in central London since 1978. It is a unique service that is commissioned as an APMS General Practice. There is also on-site provision of drop-in and emergency dentistry, counselling, legal services and advocacy, drug and alcohol and secondary/tertiary clinical 'inreach' from psychiatry, HIV and hepatology teams. All of this is delivered by multi-agency partnership working facilitated by a weekly multi-disciplinary team meeting that is open to other key stakeholders, such as outreach teams or specialist hospital-based services.

The outreach program at the centre is focused on clinical need and supported by the legal and advocacy services. What this means in practice is that the author and the lawyer from the practice go out and actively 'case find' identified targets and also opportunistically provide advice, signposting and sometimes basic care to transient homeless people across a range of locations. These include soup runs, temporary cold-weather shelters, park benches/doorways and other transient sleep sites across central London. There is also a regular clinic at a homeless women's day centre.

Approximately 70% of homeless rough sleepers are male [4], although because these statistics are subject to so many reporting biases they can only be taken as an extremely rough guide. To be counted as sleeping rough you have to be seen bedded down by an 'official' person employed in outreach capacity. Outreach workers rarely do counts on night buses or in more inaccessible areas like underground car parks or other locations off the street such as deserted hospital corridors. If you slept during the day, for example in a library, you would not be counted. These are all strategies of many homeless women and other more vulnerable homeless people, for whom the risks of sleeping in the street are simply too great.

Homelessness and mortality

All the people seen at the practice with HIV have the same the wider co-morbidities as the rest of the homeless population. We would estimate 70% of our practice population experience personality disorder and have had extremely challenging background history/life experiences ranging from experiences during military service to childhood sexual abuse.

The average age of death for a homeless person in the UK is 47 [3].

HIV in central London and homelessness

London has the highest HIV infection rates in Europe according to the literature; an estimated 1-in-8 gay men in London have HIV [5]. It should, however, be acknowledged that surveillance and testing here is more freely available than in much of the rest of Europe, so it may be that there is a more accurate picture of the problem. In Dublin, a sexual health screen typically costs at least 80 euro, and in Athens it's unlikely to be available other than privately at a similar cost, if available at all at present (personal communications with author).

HIV at Great Chapel Street

Our practice is situated just off Oxford Street in the heart of Soho and has, at the time of writing, approximately 900 permanently registered patients, with well over 30,000 people in our database of temporary patients who have presented at some time since we began keeping electronic records. Of the 900 registered, there are 32 patients with HIV we are aware of, and they fall into distinct demographic groups and behaviour patterns which reflect the wider demographic profile of HIV infection in the UK based on the recent PHE report [5].

Our practice prevalence of HIV is much higher than the national prevalence of 2.8 per 1000 [5], given we have 32 known of 900 permanent registrants, which would scale up to nearly 36 per 1000 or 3.6% of the practice population.

What are these data telling us?

These data are based on a brief retrospective analysis of electronic case notes at the practice. They are thus necessarily limited in terms of the wider conclusions that can be drawn, given the known documentation variance between clinicians and the multiplicity of Read codes; there are multiple different ways currently to code a diagnosis of HIV.

There are also reliability issues with self-report data and classification of behaviours. It is likely therefore that the proportion of sex workers is an underestimate, and similarly for injecting drug users. There is also some crossover between these groups.

Given the population we work with, a higher prevalence would be expected, although the magnitude of this is still striking, especially when considering the likely number of undiagnosed cases. However, the numbers analysed are relatively small and therefore limited inferences can be drawn from this. It clearly warrants further investigation and it would be interesting to compare data with a mainstream general practice in a similar geographic area to give a sense of how much proximity to Soho influences the statistics.

Recent data from another south London practice working with a similar population group showed an overall prevalence of infectious disease (HIV, TB, chlamydia etc.) which required treatment in 18% of new registrants [6].

Project London, which is another similar project for refugees and migrants in east London, has suggested that the level of infectious disease in new registrants who undertake screening was 13.6% during the 2011–2013 period (personal communication with author).

Great Chapel Street has a comprehensive blood-borne virus and infectious disease screening policy, and screens all new registrants who consent, regardless of immigration or documented status, at the first visit. However, the transient nature of the homeless population makes follow-up and contact tracing extremely challenging. In those infections I have had to follow up, often sexual contacts happened in migrant camps en route to the UK during sexual assault, or as part of sex work that may be the only source of income the person has.

Table 1: Homeless mortality data

	Men		Women		Both sexes	
	Mean age of death	Median age of death	Mean age of death	Median age of death	Mean age of death	Median age of death
General population	74	77	80	83	77	80
Homeless population [3]	48	47	43	42	47	46

Table 2: HIV infection, risk behaviour and demographics

	Gender	Migrant from sub-Saharan Africa	Engaged in Rx	IVDU	MSM	Sex working
Male	27	0	17	9	18	13
Female	5	4	4	1	—	5

MSM: men who have sex with men; Engaged in Rx: engaged with HIV team (from clinician's perspective); Sex working: exchanging sex for money or other things, e.g. drugs or bed for the night; IVDU: intravenous drug use.

Moreover, Public Health England (2014) [5] estimates that 24% of people infected with HIV are unaware of their infection. Many of our patients practise highly risky behaviours on a near daily basis, such as sharing needles and having unprotected sex of all varieties with multiple partners.

Men who have sex with men

It is difficult to gauge the numbers of the male practice population who have sex with men (MSM); the reporting and recording of this is very dependent on a large number of variables [7], including rapport with the clinician and sense of safety in disclosure.

It is very important that clinicians are culturally literate and able to recognise or understand sexuality and sexual practices. There are known significant recording biases in any sexual history taking [8]. There is also no systematically used method of Read coding sexuality (categorising in a searchable way within patient record in primary care), making it difficult to search for.

It is my estimation that approximately 10% of our male practice population have sex with other men, but that is entirely subjective. The men we do see who are 'out' and are homeless are, in the majority, sex working to financially sustain themselves and/or find a safe place to sleep. Many of them are relatively young and have experienced rejection from their families and communities around their sexual identity, which has led them to become homeless. Some of these will also be using drugs to prolong and enhance sex. This is referred to as 'chemsex'.

Chemsex

Chemsex parties can last for days, may involve strangers and multiple partners, and can include higher risk sexual practices. It is not usual for injecting equipment to be shared as part of the experience. Unprotected sex is common and deliberate risk-taking is part of the experience.

Many of the drugs used are not well understood, even within specialist addiction services, due to the constantly evolving nature of the compounds available. Chemsex is itself emerging as a significant contributory factor in homelessness and probably in disease transmission.

Some of the MSM who we see are migrants with no recourse to public funds (NRPF) and face many of the same issues as the sub-Saharan African women describe. Many feel too vulnerable to sexual assault or attack to sleep on the streets in locations that are accessible to outreach teams, and are thus not recognised as homeless. They are often picked up by people willing to provide a couch to sleep on in exchange for sex. Because they are not officially homeless, they cannot access 'mainstream' rough-sleeping pathways to housing and support. This creates a vicious cycle where they are repeatedly forced to have multiple high-risk encounters, and it is very challenging to support them to cope as they face a choice between destitution and sex work.

Injecting drug users

This percentage of the overall practice population is again hard to gauge reliably but is probably over 35%. Most of the HIV-positive injecting drug users we see (n=10 or 30% of all patients with HIV at the practice) probably contracted HIV through needle sharing, and the overwhelming majority are men who support their habits by street begging, major and minor crime, and exploitation of other street dwellers.

As far as it is possible to generalise, this group tends to have an extremely chaotic lifestyle focused around their substance misuse. The main drugs used are usually crack, heroin and alcohol. They are typically failing to engage with any services, they may only sporadically attend the practice and addictions services, and are rarely able to maintain even hostel accommodation. Some are not seen at all except on street outreach.

There is a very high level of co-infection with HCV (90%) in this group and a low level of awareness around the risks of transmission of HCV compared with HIV.

Women from Africa

The practice sees a significant number of migrants from sub-Saharan Africa. The women with HIV who we see are almost exclusively from this group. They will usually have travelled overland, typically from Eritrea/Ethiopia, by walking through Sudan, crossing Libya and then onto boats across the Mediterranean Sea. The hazards of this are somewhat documented by organisations such as Medical Justice Network [9] and in the mainstream media.

They are often forced into high-risk sexual encounters. Many of the women I work with have described extensive sexual abuse and gang rape at the hands of militia both in internment camps along the way and then being forced to trade sex for food, transport or simply temporary safety. Reportedly, 500 euro will get you onto the back of a lorry crossing the channel from Calais and many women spend time in Paris earning this through sex work.

These women are often unaware they have HIV, and will only be aware of HIV in the sub-Saharan African resource-poor context, where it is perceived as a more immediate death sentence. They will not typically have seen people treated with ARVs (antiretrovirals) in the context of a resource-rich publically funded health service and thus will struggle psychologically, perhaps more than someone from a different background with a diagnosis of HIV.

They may have acquired HIV, and often other STIs such as chlamydia, en route to the UK. Therefore contact tracing is extremely challenging and often unachievable. Also the only source of income they may have is to continue sex working, and this must be addressed in a sensitive way as engagement with treatment is extremely important.

The importance of case management

Case management at Great Chapel Street involves a nurse practitioner taking an overview of the care and facilitating all clinical interactions with that patient so that they have a single point of referral and focus.

This single point of access and referral is something patients report to us that they find very helpful and is well established in other fields; for example, the role of the Clinical Nurse Specialist within fields of palliative oncology.

Once someone is diagnosed with HIV at our practice they are generally added to the case management caseload so that they access extra support in navigating the healthcare system.

There are many challenges in developing a therapeutic relationship when someone is faced with many other competing priorities such as food and shelter. Often the practitioner will focus on resolving these as far as is practicable and feasible, only moving onto clinical priorities when the relationship is established.

Many of these patients are in what is referred to in the literature as the pre-contemplative stage of a cycle of change [10], if ready at all. Coming to terms with a diagnosis may be a part of this or it may not. Patients typically require intensive engagement from our entire clinical team around multiple issues such as drug and alcohol use, mental health support, dealing with past trauma, specialist legal casework around benefits and asylum in order to support them to begin to access treatment.

The limited success we have had with people who have otherwise failed to engage with the mainstream HIV team has been entirely dependent on an excellent working relationship between the HIV team who run clinics at the practice and the specialist general practice team who deal with all non-HIV issues the patient may have. The case management approach has also allowed us to develop and maintain a consistent approach to the patient in partnership with addiction services, the HIV team and primary care.

In practice this has meant methadone, ART and other medications such as iron supplements or other GP-prescribed medications being delivered by the same community pharmacist in one supervised dispensation to the patient.

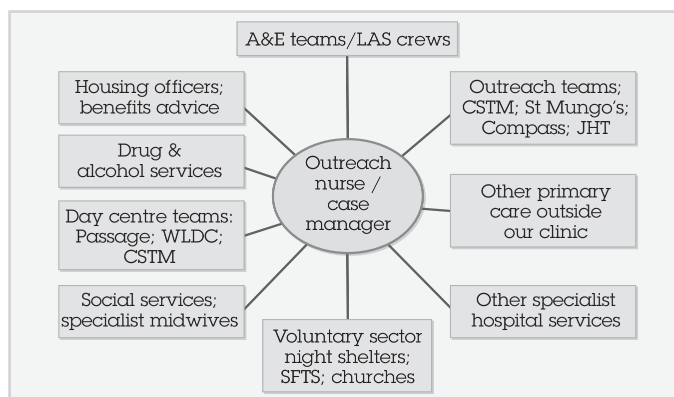

Figure 1: *Typical teams with whom I liaise during case management of a single patient.*

A&E, Accident and Emergency; CSTM, Connection at St Martin's; JHT, Joint Homelessness Team; LAS, London Ambulance Service; SFTS, Shelter from the Storm; WLDC, West London Day Centre.

Co-ordination of this single delivery of medications from three prescribing clinicians from three different health services in the community throws up some challenges, but with good inter-service communication and trust between clinicians this has been working well in the case of one patient for over a year.

Challenges of management

A fundamental point to recognise early on is that the patient group presents with a different set of priorities compared to the norm. One cannot assume that people want to engage with their health needs nor that it is their highest priority when they are struggling with addiction, homelessness and mental health issues.

Often, even when they would like to prioritise their physical health and are psychologically able to do so, there are enormous apparently insurmountable structural obstacles which need to be addressed first. For this reason our practice has a lawyer who often takes cases to court. We also seek advice from a number of expert partner agencies through regular open multi-disciplinary team meetings and maintain a constant wider dialogue about these issues through professional networks such as the Faculty for Homeless and Inclusion Health, and the London Network of Nurses and Midwives Homelessness Group.

A good level of communication is essential for effective management and partnership working. It also is essential in terms of support and clinical supervision.

This work presents significant challenges to one's professional and personal integrity. Trade-offs are constantly required between clinical imperatives, practical realities and the feelings and hopes of all concerned. These are far from ten-minute consultations and it is important to have a supportive forum in which to reflect on the issues raised.

For a practitioner there is a lack of time and resources to pursue these arguments and usually a

clinical imperative to focus on the immediately practical solutions to presenting problems. For example a patient may access free primary care but theoretically may have to pay for secondary care; this then leads to primary care clinicians managing highly complex issues that would normally be under the care of a specialist secondary care team.

Many nurses (and other professionals) will recognise that sometimes approaching health issues directly with a patient is unlikely to work and a period of engagement and relationship-building needs to take place prior to any health-related discussions. This may take months or years with some patients. Therefore, flexibility is essential, and the ability to work in a psychologically informed way is essential to success [11].

Perverse incentives and competing priorities: a case study of non-engagement

Mr B is street homeless with HIV and has been for at least 3 years following job loss. He was diagnosed over 10 years ago in the UK when he developed Kaposi's sarcoma; following successful treatment for this he then developed TB for which he was also treated successfully.

Because he has no recourse to public funds he is not eligible for free secondary care and receives no specialist input around dermatology and lymphedema secondary to his previous sarcoma. We are left attempting to manage these issues in primary care.

He previously was engaged with an HIV team but has since disengaged as questions were asked about whether he should be paying for hospital treatment by administrators. This also led to him using multiple names and dates of birth with different HIV services.

Because of entitlement issues and legal status he has no legal means of earning an income, the local authority hasn't accepted a duty to house him, and he has no means to pay for housing. He has since had syphilis and chlamydia, as well as gonorrhoea. He continues to sleep rough and is extremely depressed. His main source of income is sex work and his appearance is therefore his primary presenting health concern.

Therefore primary engagement has been around lymphoedema management and harm-reduction messages around sex working, provision of free condoms and lube, regular testing etc. We may in the near future be able to look at engaging again in HIV treatment but we are negotiating with UKBA around avoiding deportation as a priority.

Mr B is very nervous around hospital staff or staff not from our clinic. We are also providing counselling and psychological support.

Discussion

Mr B represents many disenfranchised homeless people with HIV we work with, who face multiple exclusions from society. Their struggle to access health care and maintain a modicum of basic wellness in the face of extreme adversity should be unacceptable in the high-income context that is the UK. It is imperative that nurses and allied professionals work together to challenge the status quo around this, both in terms of service design and wider advocacy. This imperative is not just moral; from the perspective of epidemiology and health economics it is also clear that if treatment is unavailable or unreachable for these people the incidence of HIV and many other infectious diseases will rise.

As Chair of the London Network of Nurses and Midwives that work with this group, I invite you to join us in facing this challenge by reviewing the experiences of homeless people accessing your service. If you believe you do not see them, you are not looking hard enough.

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