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**HIV is now a manageable long-term condition, but what makes it unique? A qualitative study exploring views about distinguishing features from multi professional HIV specialists in North West England**

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### Article

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## **Abstract**

HIV is evolving from a life threatening infection to a long-term, manageable condition because of medical advances, radical changes in health and social care policy and the impact of an ageing population. However, HIV remains complex, presenting unique characteristics distinguishing it from other long term conditions (LTCs). Our aim in this qualitative descriptive study was to identify and explore these features in the context of LTCs. A focus group (FG) method was used to gather the views and experiences of multiprofessional HIV specialists who worked in North West England. 24 staff participated in FGs ( $n = 3$ ), which were audio-recorded, manually transcribed, and thematically analyzed. We found 4 main themes: (a) stigma, (b) challenges faced by HIV specialists, (c) lack HIV-related knowledge, and (d) unique features, termed “stand-alone”. We concluded that these distinguishing features hindered full recognition of HIV as an LTC.

**Key words:** HIV, distinguishing features, long-term conditions, qualitative research

HIV is now a manageable long-term condition, but what makes it unique? A qualitative study exploring views about distinguishing features from multiprofessional

#### HIV specialists in North West England

HIV continues to be a major global public health issue. By the end of 2014, 36.9 million people were living with HIV around the world, and 2 million new infections and 1.2 million deaths were related to HIV disease (World Health Organization [WHO], 2015). In the United Kingdom, an estimated 103,700 people were living with HIV in 2014, with an estimated 24% unaware of their status (Skingsley et al., 2015). HIV continued to cause significant mortality and morbidity, resulting in elevated actual and projected treatment and care costs (Aghaizu, Brown, Nardone, Gill, & Delpech, 2013). There is still no cure for HIV, but it is widely accepted amongst professionals that with prompt diagnosis, timely initiation of lifelong antiretroviral therapy (ART), monitoring, and continued engagement in care, people living with HIV (PLWH) can expect to live healthier lives, with an expectation of a normal lifespan (Aghaizu et al., 2015). Increased global access to ART has contributed to prevention and substantially reduced AIDS diagnoses (WHO, 2013 a). This has prompted a growing consensus that HIV is now a manageable, chronic, long-term condition (LTC), sometimes likened to other LTCs such as diabetes (Deeks, Lewin, & Havlir, 2013).

Along with medical advances, attainment of LTC status has also been driven by a shift in HIV management, influenced by radical changes in health and social care, unfurled against a backdrop of an ageing population. The general population in the United Kingdom is projected to increase by 9.6 million over the next 25 years from an estimated 63.7 million in mid-2012 to 73.3 million in mid-2037 (Office for National Statistics, 2013), which will be mirrored by increasing numbers of PLWH.

Worldwide, an estimated 3.6 (3.2–3.9) million people ages 50 years and older are living with HIV (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2013). A key U.K. study estimated that by 2015, almost half of PLWH will be older than 50 years of age (Rosenfeld et al., 2013) and a newly HIV-diagnosed 20-year-old living in the United Kingdom now has a life expectancy of 70 (Antiretroviral Therapy Cohort Collaboration, 2008). Additionally, it can be argued that the transition of HIV to an LTC is driven by austerity, potentially resulting in reduction or elimination of specialist services in favor of financial gain. This is a cause for concern if the quality and financial value of services are overlooked. These issues have created a tangible push to normalize HIV care, as delivered by generalists, potentially relinquishing the need for specialist services.

The emerging debate has been that HIV is different than other LTCs, presenting unique characteristics that impact the lives of PLWH. This notion is supported by the British HIV Association (BHIVA, 2015), which has stipulated that HIV is a LTC but differs fundamentally from other, more common LTCs such as diabetes. BHIVA (2013) has alluded to the unique aspects of living with HIV in their care standards, but details about what is different and exceptional about HIV are absent.

Research related to features of HIV that can be termed exceptional, distinguishing, or unique in the context of LTCs has been limited, with much of the literature originating from Sub-Saharan Africa, which has experienced the heaviest global burden of HIV. The link between stigma and HIV has been documented frequently as an overarching issue, yet the impact on PLWH, society, and the work of HIV professionals has not been comprehensively explored. This knowledge gap may have implications for commissioners and health and social care service

providers, as limited or absent understanding and awareness of unique characteristics of HIV may render the needs of PLWH unmet and overlooked. Our study questioned (a) the existence of distinguishing features of HIV, (b) the impact of those features on the transition of HIV toward an LTC status, and (c) whether the current health and social care landscape was ready to normalize HIV.

### **Methods**

We adopted a generic qualitative descriptive research approach (Caelli, Ray, & Mill, 2003), providing a process to allow participants to explore their lived experiences and seeking to understand their views of delivering health and social care to PLWH. This was the most appropriate approach to provide a valued understanding of participants' perceptions and to contribute to evidence-based health and social care (Smith, Becker, & Cheater, 2008). A focus group (FG) method was adopted as the most effective and appropriate data collection tool to enable exploration of attitudes, knowledge, and values, through facilitated discussion using purposeful interaction. This approach allowed the emergence of new ideas and issues as opposed to testing pre-existing concepts (Kitzinger, 1995).

Purposive sampling was used to recruit a range of multiprofessional group of participants, who specialized in HIV, as they were best placed to answer the research question, providing experiential perspectives from health, social, and voluntary settings. It was important to select "information rich" participants from whom we could glean a great deal about issues central to the study (Patton, 1990). The inclusion criterion was for participants to have specialist experience in supporting PLWH. Many had previously worked with patients experiencing other LTCs, thus providing balanced discussions. Recruitment took place via National Health Service (NHS) trusts, the voluntary sector, and the local city council.

Invitations to participate were sent via email, and those who agreed were sent a participant information sheet, consent form, and details of date, time, and venue of the 3 FGs that had been arranged across 2 sites. All FGs were conducted by the first author and audio recorded. Each FG was attended by 8 participants, for a duration of 1 hour, and then transcribed. To encourage open, honest responses, maintenance of confidentiality and anonymity were explicitly requested at the beginning of each FG.

Data were analyzed manually by the first author using thematic analysis to identify and categorize key themes and subthemes whilst allowing for unanticipated themes to emerge. This was achieved by reading the transcripts; data were then manually coded, categorized, and themed. We selected the most compelling examples to provide evidence of our findings. Saturation was considered to be reached when no new themes/subthemes were identified in the final analysis of transcripts.

To validate the data and provide reliability, and clarity, four criteria of credibility, confirmability, dependability, and transferability were applied (Lincoln & Guba 1985). These were addressed by provision of a methods description detailing data collection, analysis procedures, and assurances regarding storage. The research process was supervised by a senior academic who communicated closely throughout the study. In addition, transcribed data were returned to 2 participants from each FG to assess accuracy, which was confirmed by email to the researcher. To combat any inherent bias, the first author (an HIV-specialist nurse) conducted the FGs to maintain focus on the research questions, remaining impartial and adhering to study design.

Ethical approval to undertake the study was provided by Liverpool John Moores University and Liverpool Community Health NHS trust. The study was

registered at Royal Liverpool and Broadgreen University Hospital Trust and Sahir House, which permitted FGs to take place on their respective sites and for their employees to participate.

## Results

### Sample

Participants ( $n = 24$ ) took part in three FGs (8 participants in each FG); 5 participants were male and 19 were female. Participants worked in the voluntary sector (41%), in hospital (32%), in a community health NHS trust (14%), or in the voluntary sector (13%). Job roles encompassed nurses (hospital, research, and community), social workers, support workers, educators, counselors, equality and diversity workers, therapists, and a commissioner.

### Findings

The process yielded four key themes: (a) stigma, (b) challenges to service delivery for HIV specialists, (c) lack of public/professional HIV-related knowledge, and (d) stand-alone features. Each theme generated subthemes demonstrating rich, detailed data (Table 1).

Table 1

#### *Themes and Subthemes*

Themes	Subthemes
Stigma	<ul style="list-style-type: none"> <li>• Inequalities</li> <li>• Disclosure issues</li> <li>• Judgmental attitudes/blame culture</li> <li>• Lack of peer support</li> <li>• Negative media reporting</li> </ul>
Challenges to service delivery for HIV specialists	<ul style="list-style-type: none"> <li>• Barriers to diagnosis</li> <li>• Complexity demanding enhanced case management</li> <li>• Uncertain future of specialist HIV services</li> <li>• Faith/belief systems</li> </ul>

	<ul style="list-style-type: none"> <li>• Confidentiality/sharing of information/record keeping</li> </ul>
Lack of public/professional knowledge relating to HIV	<ul style="list-style-type: none"> <li>• Burden of responsibility for PLWH to educate others</li> <li>• Fear</li> <li>• Lack of progression to normalization and LTC status</li> <li>• Difficulties raising HIV awareness</li> </ul>
Stand-alone features of HIV	<ul style="list-style-type: none"> <li>• Travel restrictions</li> <li>• Violence as a cause or consequence of HIV</li> <li>• Criminalization</li> <li>• Disproportionate mental illness</li> <li>• Communicable disease</li> <li>• Preventable infection linked to short term behavior/lifestyle</li> </ul>
<i>Note.</i> PLWH = people living with HIV infection; LTC = long-term condition.	

### Theme 1 Stigma

A majority of participants felt that stigma remained a key characteristic of HIV. As one nurse said,

That lack of info, fear and prejudice, ignorance, stigma creates a massive risk to people with HIV health at point of diagnosis, if that person thinks they can't talk to anyone, there is a risk that they may back away from health care, and then disengage, then become so sick they will need hospital. (Nurse FG1)

Across all three FGs, participants discussed how the lives of PLWH continue to be affected by internal and external stigma, profoundly affecting their health and wellbeing. Early negative media reporting was discussed in FG1 as a salient contributor to HIV-related stigma and was, therefore, considered to be a major root cause. This led to inequalities, disclosure, judgmental attitudes, blame culture, and lack of peer support. "...there is no other illness or condition I can think of that has been so vilified and sensationally reported on in the press than HIV/AIDS" (Support worker FG2).

As a consequence of associated stigma, people were driven away from



services which, in turn, created isolation, loneliness, low self-esteem, self-doubt, and vulnerability. There was a general consensus that, although some of these issues might be evident in other LTCs, they were more pronounced and complex in HIV. “When diagnosed with something else you probably have a range of people to talk to; your family, best mates. Denial can make you go underground” (Manager FG2).

*Inequalities.* Several participants were of the opinion that stigma could result in health and social inequalities for PLWH, stating that people who were already stigmatized (men who have sex with men [MSM], lesbian-gay-bisexual-transgender people, women, migrants, prisoners, and Black and minority ethnic communities), had potentially experienced additional stigma and discrimination pre- or post-diagnosis. This stigma was compounded by HIV, which then hindered or prevented access to health and social care. It was highlighted that this often resulted in poverty and financial hardship.

If somebody runs out of money, they’ve got no food and no electricity, it’s like well, go the food bank, go here, go there, but if people have got no food, how are they going to take the medication the way they’re supposed to take it? How are they supposed to keep warm? How are they supposed to take care of their health? Poverty, financial hardship, ‘cos they are more vulnerable. I’m not saying that other people aren’t but I’m saying the other people who are HIV positive are more vulnerable. But nobody seems to be taking that into account. (Social worker FG2)

One nurse felt this lead to double stigma, or a layering of stigma, as the impact often lead to additional health issues such as higher rates of drug and alcohol use, and increased incidence of self-harm, suicide, and vulnerability to sexual ill health for disadvantaged individuals. A higher rate of dissatisfaction or discrimination

from health professionals was also discussed.

I think it's important to think, actually, about previous experiences around health systems. If people vulnerable to HIV, before they were diagnosed, were experiencing health inequalities, their levels of trust and the ways that they can engage with health professionals were at a disadvantage already. So it's an extra layer, creating an extra need. (Support worker FG3)

*Disclosure.* Participants across all FGs identified disclosure of an HIV diagnosis as a distinguishing feature. This was considered one of the most difficult aspects of living with HIV, impacting on relationships with family, partners, friends, and employers. Several participants felt disclosure experiences were mixed and there was a misconception that once someone had disclosed it became easier. One participant was of the opinion that if a disclosure experience was negative, it could not be undone, which then affected how a PLWH disclosed in the future or kept the HIV diagnosis secret. Participants in one FG highlighted the difficulties of disclosure between professionals, which could complicate referrals and case discussions with other services. A majority of participants felt the main issues that prevented disclosure were immense fears of rejection or shame linked back to stigma. Supporting people to disclose their HIV status was considered a huge part of a health professional's role and not experienced in other LTCs. FG1 had this exchange:

Participant (P)2: ... and it's not just sexual or relationship disclosure either ...

Researcher (R): Who do we need to encourage the patients to disclose to then?

P1: Well we need to encourage them to disclose to as few people as possible really, and it's when things happen in life, change your job, lost a job, you

know, they've already disclosed once, and they don't want to go through all that again. You know all the connotations that come with that ... and social isolations as well, disclose socially and that brings huge isolation issues and you know...

P4: A huge part of our workload really.

P3: Especially with GPs (general practitioners), even disclosing to GPs, people are really reluctant, aren't they? [All agreed.]

From FG3:

R: So what is it preventing people from talking openly about their HIV status?

P2: I guess it's fear of rejection, fear of being judged, fear of being accused of, I guess, being guilty of not leading your life in a powerful meaningful way.

P4: It's your fault. It's blaming.

And, in FG2:

Other professionals and other social workers, you sit there on your lunch table and say you're sitting with other nurses, you know, you could discuss all your health conditions, maybe over your sandwich, never ever has anyone ever disclosed that they're HIV positive, no one would ever consider that. But, you know, any other condition, you can discuss with your colleagues. (Social worker FG 2)

*Creation of a blame culture and judgmental attitudes.* Participants in one FG discussed how people often seemed to prioritize the need to know how HIV was transmitted. This was perceived as being judgmental toward PLWH, possibly underpinned by homophobia or racism. Participants raised concerns as to how this might affect service delivery and discussed how staff can sometimes be judgmental, often laying blame on MSM for acquiring HIV, yet offering sympathy to heterosexual

women. This often created low self-esteem amongst MSM. “Patients blame themselves for their behavior and say, ‘I deserve it.’ It’s that self-loathing because they’ve put themselves at risk; you see quite a lot of as well, don’t you?” (Nurse FG 1).

*Lack of peer support.* Peer support was identified by a support worker as difficult to facilitate for PLWH as a result of stigma. PLWH can be afraid of seeing someone they knew, which could inadvertently disclose their status.

Trying to push yourself through your illness without peer support, it’s a huge struggle, more than any other group, people with HIV need it more. It’s difficult getting groups established to be the person to say, “I have HIV,” is not quite the same as putting your hand up and saying, “I’ve got diabetes.” Harder to start a support group, you can’t advertise it through GPs. (support worker FG 2)

## **Theme 2. Challenges to Service Delivery for HIV Specialists**

Participants were asked to consider what made their roles different to other specialists. The general agreement was that working in HIV care often created challenges or barriers to care delivery that increased workloads. The main issues were identified as (a) Potential or actual confidentiality breaches; (b) Difficulties in supporting those who had not disclosed to significant others, particularly during home visits; (c) Refusal to consent to refer or share information; (d) Diagnosing HIV; (e) Faith or belief systems; and (f) Complexity and concerns for the future of specialist services.

People are often unwilling give consent to allow us [to] disclose an HIV status to other professionals to get them the support they need. As professionals, this is terrible and difficult as when someone needs something, which could

potentially open some doors for them, it's horrible. Quite often people will say, "I have mental health problems or Hep C, but don't talk about my HIV." We think, "Please, let us say that as it will allow you to access support." (Manager FG2)

*Challenges related to identifying HIV as a LTC.* Participants felt that diagnosing HIV posed a greater challenge for HIV professionals than those working in other LTC, where tests and screening were more routinely offered. A nurse discussed how people were offered tests for high blood pressure, cholesterol, or blood glucose, yet the uptake of HIV tests remained low in comparison. Several participants commented that generalists continued to overlook, or miss symptoms indicative of HIV, suggesting that untimely or missed diagnoses increased the workload in terms of complexity and acceptance of diagnosis. Participants identified embarrassment and lack of confidence, skills, and interest as significant barriers in relation to generalists offering an HIV test. Self-blame, guilt, shame, fear of judgement, and embarrassment were identified as preventing people from requesting a test.

Testing and the inequalities around testing and actually accessing a diagnosis, and you, in the main, you have to make a decision yourself to be tested for HIV and that's ... I would say that that's different from other LTCs. An HIV infection is pretty much hidden, whereas you may have some symptoms of other LTCs which compel you to go to seek medical advice and you don't have to say, "I want to be tested for diabetes" or "I want to be tested for COPD (chronic obstructive pulmonary disease)." They just offer it. You can rely on the on the clinician to do it. It's different, the fact that HIV testing isn't more normalized, more prevalent. That sets people up right from the

beginning because you have to reveal that you've potentially been exposed to so you're on the back foot already. You have to come out and say, "Well actually I might have been exposed to HIV," and right there, that's vulnerability in itself. How [can] you find an appropriate place to test with confidence? It's not straight forward, you have to seek it. (Support worker FG2)

*Complexity in HIV management and care.* Participants across all FGs identified complexity as a significant issue within their roles, demanding enhanced case management. There was an acknowledgement that complexity was evident in other LTC, such as mental health, or poorly controlled diabetes, but participants alluded to how complexity often focused on the medical aspect of the condition and not on psychosocial characteristics, which they felt complicated HIV care planning and service delivery. An ageing HIV population was also discussed by some as exacerbating complexity. Most participants said they felt significantly and comprehensively more involved with their patients, for longer periods, than their counterparts working in LTCs. They felt that they often became the default or key worker, describing how PLWH could be reluctant to access generalist health and social care due to stigma and how this could blur professional roles. This required additional support to help PLWH remain engaged in treatment and care. One social worker stated:

I think one of the distinguishing features is social complexity. Say if you've got dementia referrals, asylum seekers, and people with HIV, it's like a multi-layering of issues there which you're working with and it's completely not straight forward. Very, very complex. Often in HIV you've got people in a different age group, you know younger people going right across up to people in their 60s, particularly with the social care issues you got. High risk of

homelessness as well. Home care and adaptations, as well you know, older people with HIV now looking at going to sheltered accommodation or care homes and younger people disabled 'cos of late diagnosis. Mental health issues as well. You've got to consider people's immune systems in suitable housing, people with children as well. (Social worker FG2)

*Uncertain future of specialist HIV services.* This subtheme emerged as an overwhelming concern by participants, stating that in recent years, more common LTCs have had specialists replaced by generalist health and social care professionals. Some expressed concerns for the potential decline in health and wellbeing of the people they supported. There was a consensus that generalists, such as GPs, nurses, and social workers, should be actively involved in the care of PLWH, with specialists undertaking more of an education/support/research role. However, there was a firm agreement that society and professionals do not perceive HIV as "normal," hence a reduction in HIV specialist input would be detrimental to PLWH. FG3 dialogue focused on the financial value of specialists iterating that without them there would be a higher prevalence of late diagnoses, requiring hospital admissions and more care, costing more in the long term. "The need for specialist HIV workers is paramount. If we lose that provision we are back in the dark ages, the tombstone days" (Educator FG3).

Participants described their roles as educators, communicators, and advocates of normalization. "The specialists are the communicators and the educators, so they're the ones that need to [be] vested in at the moment, to go out and spread the word so that the normalization is that you can go anywhere" (Support worker FG3).

I'm scared for people with HIV and specialist care, because the smaller

numbers and lack of a strong powerful voice ... is smaller than Macmillan, for e.g., or British heart foundation. HIV doesn't seem to attract sympathy. It's harder to advocate, always fighting for our patients. (Support worker FG2)

*The influence of faith or belief systems on HIV care.* The impact of faith or belief systems was identified in one FG as a relatively recent feature in the field of HIV, which compounded complexity and challenged care provision. It was highlighted that when individuals prioritized faith or belief systems over medicine, initiation of ART could be delayed. Additionally, engagement and retention in care could be negatively affected. This increased the risk of sexual and vertical transmission, impacting public health and causing detriment to individual health and wellbeing.

I have had experience of service users withdrawing from services because of family members and friends encouraging them to, based on faith or belief systems. They have said things like, "God will cure you, it's your fault, you are in this on your own, or listen to us and do what we say and you will be fine." Preaching, "God will cure you when you go to church, do as you are told and you will be cured." More disturbing is that when I found out the relative's profession was in health care. They have been trained surely? What do those professionals say to their patients? Professionals face difficulties then, in working with families. What do we say? It creates a dilemma. This is [an] incredibly difficult situation to work with. You hope social structures are there to support people with HIV, sometimes they are not and they are against you. You have to almost fight against it on behalf of the service user. (Social worker FG2)

Participants in one FG felt that engaging with faith leaders was a challenge to



HIV professionals that required sensitivity and innovative practice. The participants acknowledged the responsibilities faith communities and faith leaders had to challenge stigma and to promote HIV prevention, testing, and treatment.

*Confidentiality: Information sharing and record keeping.* Participants stressed that confidentiality issues, particularly in relation to information sharing and record keeping could present anxiety, frustration, and professional dilemmas, particularly when they did not have consent from the patient to share information. The lack of consent to share can result in non-receipt of entitled benefits and services, which was different from other LTCs because the reasons for non-consent were identified as fear of stigmatizing responses, discrimination, or rejection. “Confidentiality issues, sharing information is a real restriction, need permission, I think HIV nurses then can’t always share information that’s important, so you can’t talk to members of the multidisciplinary team making things a lot more tricky” (Nurse FG3).

An HIV diagnosis makes it harder to work with people. So many different barriers, which you don’t come across in other conditions, it’s completely different; confidentiality, their wishes, and how they want information sharing, how they perceive themselves, too. They are scared of negative responses.

(Manager FG1)

### **Theme 3. Lack of Public/Professional Knowledge Relating to HIV**

Participants in all the FGs felt there was a continued lack of knowledge, skills, and expertise about HIV amongst other professionals and society in general stemming from fear, stigma, and lack of public health information/campaigns.

*The burden of responsibility for people with HIV to educate others.*

Participants believed that lack of knowledge amongst professionals and the public created a burden of responsibility for PLWH to educate not only family and friends,

but also health and social care professionals about the infection. One support worker felt this could negatively affect the health and wellbeing of PLWH by creating unnecessary stress and anxiety. Other participants agreed that, although evident in other LTCs, it was heightened in HIV, causing people to revisit a potentially traumatic diagnosis.

You may well be disclosing on the basis of sharing to get some form of support. But actually you may well find you are placed in the position of educational expert and that position of actually needing support is completely denied to you. So you have to educate your GP, your family, everybody around you and you are placed in the position of having the responsibility of expertise around your own condition which gets in the way of you actually getting your needs met. (Therapist FG3)

I know when patients have plucked up the courage to tell their GP about their status if it's away from the city center where the prevalence rate of HIV is less. When I say, "Well how did it go?" and they went, "Oh it was great, I ended up being with a GP for half an hour and the GP wanted to know all about HIV, in the end I forgot what I'd gone there for." (Nurse FG1)

*Societal fear.* The study participants felt that fear was heightened in HIV, with lack of knowledge as a key cause. A discussion in FG3 argued that fear had been used in public health messages about HIV, especially in the early days, for example the tombstone image used in public health information on television. Instead of educating the public, it exacerbated the fear surrounding HIV and people still related to it today. Moreover, participants reaffirmed that fear could result in barriers to testing, negative health impacts, and lack of compassion for professionals and the general public.

Fear? It's all about personal fear whether it's your mate telling you they're HIV positive or me as a student nurse being told to pass someone's dinner under the door, it's around fear of infection. As a nurse watching people get diagnosed with cancer, I see sympathy, people going around every night, taking bottles of wine, meals, and you're diagnosed with HIV and even if you do tell people the sympathy [is] just not the same. (Community HIV nurse FG2)

*Slow progression to normalization of HIV to LTC status.* There was a general consensus that limited knowledge about HIV within society and professionals was hindering the reclassification of HIV from a life threatening infection to a manageable LTC. Many participants felt that the drive to normalize HIV was, therefore, unrealistic. Participants in one FG were of the opinion that PLWH still confronted the same psychosocial issues today as in the pre-ART era, describing the transition as static. "You know, we keep thinking we've moved on 'cos we do this job -- But we haven't, the stupid thing is that, you know, 30 years on we're still talking about things like this" (Research nurse FG1). "In my experience we are still with the 90s tombstone, that's what I hear week in, week out from health and social care professionals. It hasn't changed" (Support worker FG2). Despite the drive by HIV professionals to scale up education and training for generalists, specific training is no longer commissioned because HIV is now perceived as normal, "But it's not normal, and seen as someone else's problem" (Commissioner FG3).

*Lack of public health campaigns/difficult to raise awareness for HIV.*

Participants in two FGs felt that raising public health awareness was more difficult for HIV than other LTCs due to lack of knowledge. HIV was sometimes included in national fundraising events and campaigns such as Comic Relief and Children in

Need, but participants were of the opinion that these often promoted the same stereotypical images, and were Africa centric, fueling public perceptions. Participants expressed concerns that PLWH were in danger of being forgotten as knowledge and awareness remained limited. Participants discussed the U.K. public health campaign from the early 1990s, which involved television commercials and leaflet drops containing images of a gravestone, had stayed in the minds of public and professionals alike, and suggested that this should now be replaced. “Why aren’t governments putting HIV on the map like cancer, like diabetes, like dementia?”

(Social worker FG3)

It feels like HIV services are ripe for the kicking not the picking. It’s a very marginalized group made up of even more marginalized people, you don’t get as many people wanting to stand up for their rights and raise awareness for fear. Do people assume people’s needs are being met because they don’t hear about it, or are they being willfully ignorant? It is morally and ethically saddening and disheartening.” (Support worker FG2)

#### **Theme 4. Stand-Alone Features of HIV**

A diverse range of stand-alone features unique to HIV also emerged from the data. These are discussed below.

*Travel restrictions.* Two nurses indicated that travel restrictions and bans to enter certain countries were in place for HIV. Although restrictions applied to other LTCs, they usually related to health insurance and were not country specific. The bans and restrictions in place related to HIV, however, were different and were an attempt to control transmission. Participants were of the opinion this was discriminatory and related to lack of knowledge, fear, and stigma. One social worker felt that such restrictions could significantly impact PLWH psychologically, as there

was potential for HIV to be disclosed on arrival to certain countries. This could result in detainment and deportation. Participants related that disclosure could happen via involuntary testing, discovery of medications, physicians' letters, HIV literature, or correspondence found in luggage.

You still can't enter Saudi Arabia with HIV, and it was only actually until 2012 when you could go to America. One of our ladies was getting married. She was going to Mexico, they paid 5000 pounds for their honeymoon and marriage but they had to have a HIV test. She was already positive and had treatment so couldn't go as they insisted they have an HIV test before they travel. (Nurse FG1)

A participant in FG3 discussed how there were fewer countries that still banned tourist travel for PLWH, but more imposed restrictions for longer stays or prevented relocation.

*Violence.* Some participants were of the opinion that violence could be a cause or consequence of HIV, particularly for women, which may be more covert than for other LTCs. It was thought that transmission occurring from a violent incident profoundly affected how someone dealt with HIV from the outset.

"Transmission could be a number of different ways and that potentially could be where someone's been violently assaulted or that kind of thing, that's completely a different ballpark, to start your life with a LTC" (Therapist FG3).

Additionally, some participants felt that people with HIV experienced violence and abuse after diagnosis, usually by a threat of disclosure to others. One therapist felt that those who acquired HIV from violent/abusive incidents often had a history of abusive relationships. This could lead to future difficulties in negotiating sex or accessing support.

*Criminalization.* Criminalization was highlighted by a nurse as unique to HIV and differentiating it from other LTCs. Participants suggested that fears related to disclosure were often linked to fears of prosecution and the two issues were closely meshed. Actual and potential accusations and prosecutions have been incredibly complex and traumatic, impacting the health and wellbeing of both PLWH and professionals. Participants agreed that the law was unhelpful and harmful to public health.

I would like to stop the person doing this to somebody else but I don't know how. Taking that down the legal route, that patient would then potentially be exposing their own status to the media, to their family, and everybody else and no other LTC questions people ... questions people's promiscuity or lack of in court or ... there's all of that. (Community HIV nurse FG3)

*Mental illness.* Mental illness, albeit an LTC in its own right, was felt by participants as disproportionate in HIV, with more pronounced effects in PLWH. Some were of the opinion that in other LTCs, mental illnesses, such as depression, were usually the result of disability and subsequent inability to work. However, in HIV, participants felt key causes of mental illness could originate from traumatic events, social stigma, and anxieties related to transmission and disclosure. Participants also felt that low self-esteem and social isolation were significant in the development of mental illness. "Mental health implications, suicidal ideation, completed suicides for HIV-positive people, are disproportionate to other conditions" (Manager FG2).

*HIV is communicable.* Study participants felt that because HIV was communicable, transmitted vertically, sexually, or via injection drug use, rendered it different from other LTCs. They suggested that the added fear, stress, and anxiety of

transmitting HIV resulted in immense strain, especially during pregnancy, which could negatively affect health and wellbeing. “These are very specific and unique conditions, needing incredibly sensitive and specialist support as it can potentially impact on an entire family” (Therapist FG3). Participants in one FG discussed the link between decreased infectivity and undetectable HIV viral load, yet significant anxieties related to transmission still existed.

Someone with HIV I worked with said she disclosed and was having sex but the anxiety it caused was ridiculous even though she was undetectable. She then became celibate as she couldn’t stand the strain of passing on her infection even though she knew the risk was really low. (Nurse FG1)

*HIV is preventable.* Some participants acknowledged that other LTCs were also preventable by changing behaviors such as smoking, alcohol excess, or poor diet. However, those diseases usually manifested after many years of a risky lifestyle. It was felt that HIV differed, as it could be acquired at any point during unprotected sex or injection drug use with someone who was undiagnosed. This rendered health promotion interventions more challenging and required different approaches. “There’s no opportunity for prevention on a one-to-one basis, so needs public health campaigns but not the tombstone” (Social worker FG 2)

Smoking and alcohol can contribute to other LTC but over a long period of time, so professionals have more time to work on health promotion and prevention. You only need to have unprotected sex once with maybe someone who doesn’t know they have HIV and bang; there you go; you have it too. (Support worker FG2)

### **Discussion**

The central aim of our study was to explore the opinions and experiences of

HIV specialists working in a variety of job roles in relation to distinguishing features of HIV in the context of an LTC. The study participants revealed comprehensive perceptions about what makes HIV different or unique; the more prominent issues are discussed in this section.

Stigma was identified as a lingering issue, rooted in negative media reporting. Stigma and its effects on PLWH were discussed in studies early on in the epidemic (Foreman, Lyra, & Breinbaur, 2003) and in newer studies (Dybul & Kirby, 2014) concluding that, over the years, HIV-related stigma has remained stubbornly present. Stigma has been described as a main barrier to implementing effective strategies to combat the HIV epidemic (Majajan et al., 2008) and can often be misunderstood due to complexity and poorly defined underlying issues (Connell et al., 1991).

Underserved populations already experience stigma and discrimination, which are considered to be root causes of inequalities and which can be exacerbated by HIV. This link has been supported by several studies (Magadi, 2011; National AIDS Trust, 2007). To illustrate this further, the prevalence rate of HIV was approximately 30 times higher for MSM and Black Africans compared to the general population in England, remaining highest in the most deprived areas (Agaizu et al., 2013). An HIV diagnosis can also result in financial hardship due to inequalities in accessing services. Radcliffe (2012) also acknowledged that poverty was the main source of poor health for PLWH. Individual, societal, and structural factors such as sexual behaviors, infections acquired abroad, migration, housing, education, HIV-related stigma, and discrimination have contributed to a layering of inequality resulting in even greater disadvantages. Holmqvist (2009) stated that HIV has often been termed a disease of poverty, but would be more appropriately described as a disease of inequality.



Fear of disclosure may result in neglect of health and wellbeing (Morton 2014). Additionally, potential disclosure can evoke feelings of shame and fear leading to abandonment and isolation, and findings have shown that stigma perpetuates judgmental attitudes leading to a blame culture (Dlamini et al., 2009). Similarly, Macfarlane (2014) identified subtle ways that nurses differentiated the care given to PLWH, by judging whether someone contracted HIV “innocently” or not.

Distinguishing features of HIV can create barriers to care delivery that many participants felt were not experienced in other LTC. For instance, HIV testing. Champenois (2013) found that individuals not perceiving themselves as at risk for HIV, in conjunction with a failure of health care professionals to offer HIV testing, led to missed opportunities for diagnosis, a common difference between HIV and LTC. Delayed HIV diagnosis has not only affected individual treatment outcomes, but also impacted public health in relation to transmission, and contributed to even more late diagnoses (BHIVA, 2008).

The value of enhanced case management is increasingly apparent in HIV, becoming more complex with an ageing HIV population. Ageing increases requirements for social and clinical support from health care providers, including community nurses (Peate, 2013). PLWH face major challenges in the future with complex health problems, scarcer financial resources, and greater isolation than many of their peers (Perry, Bennett, Jones, Janes, & Roberts, 2013).

The drive toward HIV attaining LTC status, demanding more generalist care, might indicate an uncertain future of specialist HIV services. However, a general lack of knowledge and skills, compounded by stigma and tangible negative attitudes, have rendered the transformation of HIV to an LTC untimely. Deeks et al. (2013) stated that the need for HIV specialists was due to a requirement to manage an

incurable chronic disease, without the prospect of an imminent cure. Perry et al. (2013) added that PLWH still had concerns and anxieties related to accessing generalist services because of trust issues and fear of stigma.

The impact of faith or belief systems emerged as a newer issue which is under researched in the UK and globally. PLWH can seek strength and support in religious affiliation to cope with living with HIV, particularly in African communities (Chinouya & O'Keefe 2005). However our study highlighted that faith can sometimes be a barrier to care delivery which conflicts with science and medicine. This can undermine the health and well being of PLWH. Some Black Africans and faith leaders foster the belief that faith can prevent HIV transmission and prayer can cure HIV without medication (Ridge et al 2008). Chinouya & O'Keefe (2005) suggest the church can be a threatening place in relation to confidentiality and suggest partnership working amongst statutory providers and faith leaders to alleviate stigma and offer support to PLWH. Faith communities and their leaders therefore have a key role to counteract stigma and to promote HIV prevention, testing and treatment in collaboration with multi professional teams.

Our study findings demonstrated that confidentiality issues created barriers to care delivery in HIV despite updated guidance on patient privacy (National AIDS Trust, 2014). This remains a complex issue, creating professional anxiety about when and when not to share sensitive medical information.

Several characteristics of HIV were deemed as unique to or featured more prominently in HIV than in other LTCs. One such characteristic was disproportionate mental illness. Whetten, Reif, Whetten, & Murphy-McMillan (2008) listed the most common mental health conditions in HIV as depression, anxiety, and post-traumatic stress disorder. Engbretson (2013) described how PLWH also diagnosed with a

psychiatric illness could be shamed, ostracized, isolated, discredited, and socially and economically marginalized.

Violence can be a cause or consequence of HIV, particularly for women, which does not feature as prominently in other LTCs. Transmission occurring from a violent incident profoundly affects how a person deals with HIV from the outset. Additionally, PLWH can experience violence and abuse after diagnosis, usually as a threat of disclosure to others. Violence against women and girls with HIV has been defined as “any act, structure or process in which power is exerted in such a way as to cause physical, sexual, psychological, financial or legal harm to women living with HIV” (Hale & Vazquez, 2011, p.13 ).

There is an undeniable link between violence against women and girls and HIV, underpinned by increasing international evidence that has suggested that women who had experienced violence were 50% more likely to acquire HIV compared to women who had not experienced partner violence (WHO, 2013).

Criminalization does not feature in other LTCs. Fears related to disclosure have often been linked to fears of prosecution, closely linking the two issues. Actual and potential accusations and prosecutions are incredibly complex and traumatic, impacting on the health and wellbeing of PLWH and the care professionals involved. In the United Kingdom, prosecutions for reckless transmission of HIV have occurred (Phillips & Poulton, 2014); global recommendations have been to limit the use of criminal law, preferring a non-punitive, non-criminal approach to HIV prevention (Oslo Declaration on HIV Criminalization, 2012; UNAIDS 2008). Key U.K.-based stakeholders have concurred with this recommendation, stating that the law has been unhelpful and potentially harmful to the public health.

HIV is a communicable disease, transmitted sexually, by sharing injection

equipment, or from mother to child, which renders it unlike other LTCs. The added fear, stress, and anxiety of transmitting HIV to another person can be an immense strain, especially during pregnancy, negatively affecting health and wellbeing. Despite evidence about the substantially reduced risk of transmission when a PLWH has an undetectable viral load (Rodger et al., 2016), anxiety and fear related to transmitting HIV persist. HIV is preventable, as are other LTCs, but the latter may be attributable to long-term behaviors such as smoking, poor diet, excess alcohol, and drug use. The opportunity for health promotion is, therefore, greater as these diseases take longer to manifest. In HIV, a transmission can result from a one-time or short-term exposure that renders health promotion and prevention strategies more difficult to implement.

### **Conclusion**

Our study has explored, illuminated, and collated the features that distinguish HIV from other LTCs, providing insight for key stakeholders working in health and social care, as well as in voluntary services. Greater understanding of the uniqueness of HIV can positively influence commissioning, planning for, and delivering services for PLWH, allowing unmet needs to be prevented or addressed. Our study illustrated how characteristics of HIV can prevent PLWH from accessing generalist services. This reinforces the current need for HIV specialists, without whom continued, vital engagement with PLWH may be lost. This can impact retention in treatment and care, which not only optimizes health and well-being via meaningful engagement and effective ART, but also contributes to prevention strategies. Despite major scientific and health care advances, our study concludes that distinguishing features of HIV currently hinder normalization and reclassification of HIV to an LTC status.

### **Limitations and Strengths**

Participants in our study worked in health care in North West England, which limits our findings due to the specific nature of HIV prevalence and services available. There were no physicians in any of the FGs, which may have added value by adding an additional profession with specific knowledge and skills. The drive toward HIV being classed as a LTC is a global issue that reinforces the timeliness of our study, adding value and information to the discussion. Additionally, our participants supported PLWH in their jobs, allowing rich experiential understanding of the issues faced by their clients, enhancing exploration of features that distinguish HIV from other LTCs.

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### **Key Considerations**

- Unique features of HIV distinguish it from other long-term conditions (LTCs).
- Distinguishing features can prevent PLWH from accessing generalist services, reinforcing the current need for HIV care specialists, without whom continued vital engagement may be lost.
- Understanding the unique features of HIV can help to address the unmet needs of PLWH, and may help to optimize health, well-being, and retention in treatment and care.
- Nursing, health, and social care providers need to accumulate a greater understanding of how HIV differs from other LTCs.