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Speaker Name	Statement
Pauline Jelliman	No interests to declare
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It's just like diabetes: a qualitative study exploring views about distinguishing features of HIV in the context of long term conditions from MD HIV specialists in Liverpool

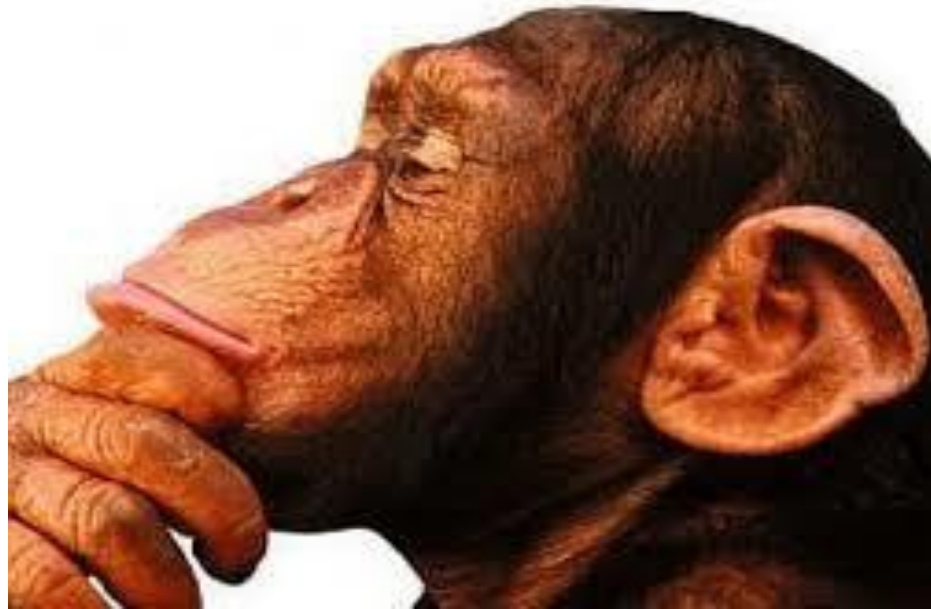
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Study Rationale

- Effective ART
- Changing NHS
- Emphasis on self care
- Ageing population
- References to “exceptional features”
- Limited literature to evidence

Research question;
What are the characteristics which
make HIV different / unique?



AIM

To illuminate & explore distinguishing characteristics of HIV in the context of LTC, and assemble findings in 1 study.



Study Design

- Qualitative/descriptive study
- Purposive sampling = recruited from 4 organisations
- Method = 3 MD FGs conducted over 2 sites totalling 24 participants, P.I.S., consent, & demographic form provided



Data Collection & Analysis

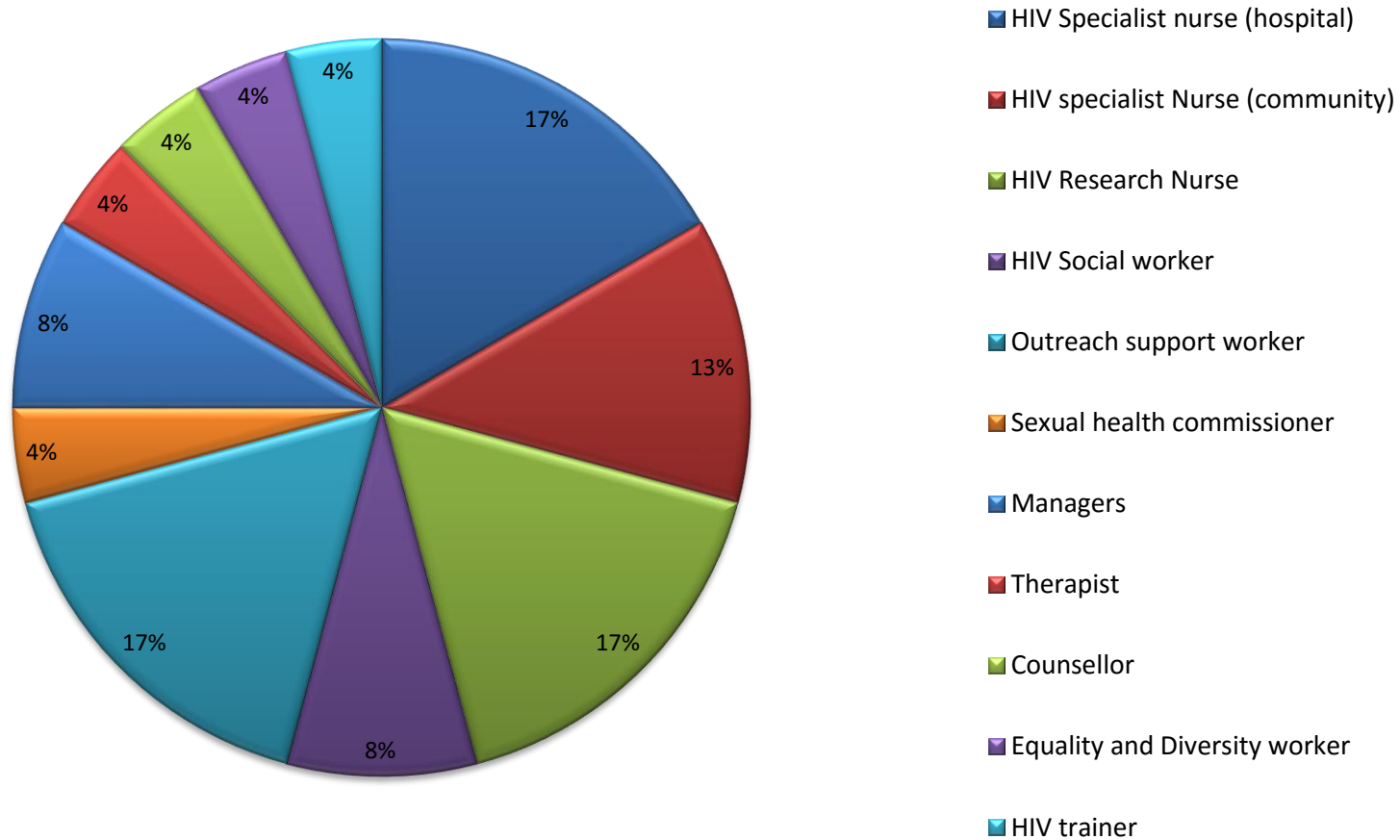
- FGs were audio recorded & transcribed verbatim
- Data was managed and analysed manually using thematic analysis; coded categorised & themed
- Saturation was reached as no new themes / sub themes were identified in the final analysis of transcripts

Ethics

- Full ethical approval granted from LJMU, permission for FGs granted from key stakeholders
- For reliability, clarity and validity, 4 criteria were applied credibility, confirmability, dependability, and transferability (Lincoln & Guba 1985)

Sample

Participant's job roles



Results

4 key themes were identified each generating sub themes providing richness to the data

- “Stand alone” themes = 6
- Lingering stigma = 5 sub themes
- Challenges to HIV professionals = 5 sub themes
- Lack of public / professional knowledge relating to HIV = 4 sub themes



Results; Theme 1

“Stand alone” features of HIV

Preventable infection linked to short term behaviour/lifestyle

Travel restrictions

Communicable disease

Disproportionate mental illness

Criminalisation

Violence as a cause or consequence of HIV

Preventable infection linked to short term behaviour/lifestyle

“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”

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 ball-park, to start your life with a LTC”

Violence as a cause or consequence of HIV

Communicable disease

Results; themes 2,3,4

THEMES	SUB THEMES
Lingering stigma	<p>Inequalities</p> <p>Disclosure issues</p> <p>Judgemental attitudes / Blame culture</p> <p>Lack of peer support</p> <p>Negative media reporting</p>
Challenges to HIV specialists	<p>Barriers to diagnosis</p> <p>Unique complexity demanding ECM</p> <p>Uncertain future of specialist HIV services</p> <p>Faith/belief systems</p> <p>Confidentiality/sharing of information/record keeping</p>
Lack of public / professional knowledge relating to HIV	<p>Burden of responsibility for people with HIV to educate others</p> <p>Fear</p> <p>Lack of progression to normalisation and LTC status</p> <p>Difficulties in raising HIV awareness</p>

Stigma; theme 2

*“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”*

*“.. **stigma** just shuts people up and I still see and hear so many health and social care professionals think you can still get it from a toilet seat, tooth brushes, from all sorts of ways other than sex.”*

“some feel they can’t **disclose** socially and that brings huge isolation issues.”

“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”

Challenges to HIV professionals; theme 3

Diagnosing

“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. HIV 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”. 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 normalised, more prevalent. That sets people up right from the beginning because you have to reveal that you’ve potentially been exposed. 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 you find an appropriate place to test with confidence? it’s not straight forward, you have to seek it.”

“There are huge barriers to diagnosis that don’t exist in other LTCs, embarrassment, fear, self-blame, shame.”

Challenges to HIV professionals

Uncertain future of specialist HIV services

“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, advocate allowing normalisation.”

“The need for specialist HIV workers is paramount. If we lose that provision we are back in the dark ages, the tombstone days.”

Challenges to HIV professionals

Information sharing / confidentiality

“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 freely to members of the MDT making things a lot more tricky”

“People are often unwilling give consent to allow us 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”

Lack of public / professional knowledge relating to HIV; theme 4

Burden of responsibility for someone with HIV to educate others

“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’re 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”

I know when patients have plucked up the courage to tell their GP about their status if it’s away from the city centre 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”

Lack of public / professional knowledge relating to HIV;

Lack of progression to normalisation and LTC status

“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, thirty years on we’re still talking about things like this”

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”

Lack of public / professional knowledge relating to HIV;

Lack of Public Health campaigns/ difficult to raise awareness for HIV

“It feels like HIV services are ripe for the kicking not the picking. It’s a very marginalised group made up of even more marginalised 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 wilfully ignorant? “

“Why aren’t government putting HIV on the map like cancer, like diabetes like dementia? “

Limitations & Recommendations

- Potential bias as researcher is an HIV specialist
- Study may not translate nationally as services, therefore experiences, may differ
- Would benefit from national views and views of people living with HIV



Conclusions

- The distinguishing features of HIV have been identified, explored and assembled together in this paper for ease of reference by commissioning bodies and provider organisations.
- The research may impact on nursing, health & social care by the provision of a comprehensive evidence base promoting a greater understanding how HIV differs from other LTCs. It is hoped the impact will result in services which are “fit for purpose” thus addressing unmet need. This should optimise health, well being, & retention in treatment & care.
- Distinguishing features can prevent people with HIV from accessing generalist services, reinforcing the current need for HIV specialists, without whom, continued, vital engagement may be lost.
- The research reaffirms that despite effective ART, progression towards normalisation is hindered by distinguishing features.

“Policy makers say oh HIV is now just a LTC like diabetes in order to justify their cuts to our services, how very far we have to journey together to shift our and the public’s thinking as to what HIV means in our lives. I look forward to the day when people newly diagnosed with diabetes can be comforted if they are told oh, diabetes is now just a LTC like HIV. Maybe then we will all have something to celebrate together and we can all hang up our activist cloaks for good.”

Alice Welbourne 2011

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