

Patients' perspectives on the development of HIV services to accommodate ageing: a qualitative study.

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INTRODUCTION

As increasing numbers of people with HIV reach older age, services will need to adapt to meet the needs of patients with age-related comorbidities. Issues surrounding the care of an ageing population include polypharmacy and the risk of drug-drug interactions in the context of multiple prescribers.

AIM

- 1) to establish what aspects of health care are most valued by people living with HIV
- 2) to identify patients' concerns and preferences for the future delivery of HIV care
- 3) to identify patients' concerns and preferences for the future care of age-related comorbidities

METHOD

Twelve focus groups of patients receiving HIV care, conducted in community settings in south east England. Groups quota-sampled based on age, sex, sexual orientation, and ethnicity. Data analysed using Framework Analysis.

1. GP practices are felt to lack understanding of patient experience and confidentiality

Patients' concern around confidentiality and the capacity of GP practices to deal appropriately with the emotional and social aspects of living with HIV support patients' reluctance to use GPs.

Confidentiality concerns

Two types of confidentiality concerns:

1. GP receptionists were frequently seen as weak points in confidentiality – due to lower levels of training and their position in the local community.
2. Access to patients' HIV status in GP records was also a concern – relating to external agencies (employers, financial services) and reception/administration staff. There was inconsistent understanding about whether patient records (GPs and/or secondary care) were held on computers or on paper, and no consensus about which would be better for assisting communication or maintaining confidentiality.

Participants expressed widespread dissatisfaction and lack of confidence in GP's understanding and appreciation of the social and emotional experience of living with a highly stigmatised illness.

This contrasted sharply with patients experience of HIV clinics and further undermined the perceived value of GP services.

"...if reforming of HIV services is going to be taking it back to the GPs, then there has to be mandatory training...around the sensitivity and the way they talk to people; so not just the medical stuff, they need to understand the emotional and psychological side of things ..."

Non-African Women under 50.

Three key themes

3. GPs' low levels of knowledge, skills and confidence in treating HIV

Patients perceive a lack of HIV skills and experience among GPs, which represents a significant barrier to the acceptance of GP involvement in their care.

While examples of excellent GP care were cited – usually related to individual GPs – most discussion about GPs focussed on a perception of GPs' limited capacity to manage HIV.

"... the GP I have at the moment, his attitude to whenever I go and see him is 'Oh that must be HIV related, you need to go to the hospital'. So I try and make an appointment at the [HIV clinic] but they're overstretched as everybody knows and they don't have time to be dealing with coughs and colds."

MSM 50 and over.

2. Concerns around care-coordination and communication between services

Shared-care arrangements for patients with HIV have developed inconsistently and were seen to lack clear responsibilities for prescribing, referrals and care-coordination.

Participants report that fragmentation of care between GPs, HIV clinic, and other departments and/or Trusts has increased their vulnerability in three ways: -

1. increasing number of clinical relationships;
2. stressing the efficiency of communication; and
3. delaying the exchange of medical info/updates between depts. – sometimes with serious implications.

"...at one stage I had four NHS Trusts looking into different bits. My GP hasn't a clue what's going on with my care. My HIV doctor has a more holistic view, but four NHS Trusts working on slightly different bits and trying to investigate what was causing me to go dizzy, not talking to each other. ...And in the end I was saying to them, 'No, you're causing me to have mental health problems' – not because of what I'm dealing [but] because I'm trying to deal with four different NHS machines". MSM under 50.

Patients develop strategies to compensate for weaknesses in care-coordination

Strategies included: -

- restricting their care to one hospital/Trust
- becoming expert patients (which was sometimes seen as being a 'difficult patient' by non-HIV services)
- asking for (not always receiving; sometimes having to pay for) copies of letters and test results
- maintaining a parallel record of every procedure and result
- changing clinics or GP practice
- charming and/or cajoling staff
- making formal complaints.

"... any correspondence about me I want a copy. If there are any tests performed then I will want a copy of those. Now tomorrow morning at nine, I have an appointment with the GP, merely to get copies of test results that I can't get any other way. But that's burdening up the GP's time." MSM 50 and over.

Referrals processes

Participants report that services seldom communicated the method, expectations and processes of shared-care and referral. Participants in every group reported GPs referring patients back to specialist HIV clinics for three reasons: -

1. Because the GP lacked confidence or skills to prescribe in the context of HIV drug interactions
2. Unclear and ill-defined responsibility for prescribing for patients with HIV
3. Confusion over which service had responsibility and/or capacity to make referrals to secondary care

"The GPs don't understand anything about HIV because even if you go with just a slight fever or cold they always say 'We don't know what medication to give you because it might interfere with your HIV medication so I think you go back to your consultant!'" African Women 50 & over.

"[It] took me to come-and-go to three consultations to get the vaccination done because I went to the GP they say No; I went to the HIV and she said Yes; and I went back to the GP and I got it" Non-African Women under 50.

"I went to the clinic, as a walk-in and they said we want you to go to your GP and they'll refer you to the hospital for the abscess. So I made an appointment and I told [the GP] and he said 'The NHS doesn't work like that, I need a letter, there should be a letter, you haven't got a letter, go back to the clinic and get a letter'. I didn't accept it - I wasn't moving, I wasn't going back again to do this thing, and he agreed to refer me." Non-African Men 50 and over.

Variations by degree of comorbidity and/or years since diagnosis

Significant divisions in the data between participants' with more comorbidity/years-since-diagnosis, and those more recently diagnosed and/or in good health. This was more predictive of differences than >/<50 age sampling.

These differences influenced experience of services and perspectives on the structure and provision of services. Those with greater use of services tended to be more dissatisfied with services and had greater reliance on specialist HIV clinics.

"A group like ourselves, [...] who have been diagnosed for a long time, our health issues are different to a person walking into a clinic maybe 26years old, recently diagnosed [...], and they do try to explain that to some of the junior doctors: 'these are older patients who have been diagnosed for ten, fifteen, twenty years'".

MSM 50-and-over.

Variations by region / degree of HIV prevalence

Since these focus groups were held in areas of high prevalence (London & Brighton) regional bias is expected, but references to other areas and contexts featured in the groups:

Participants from provincial/lower prevalence areas (Sussex, Surrey, Liverpool) spoke of travelling or moving permanently to higher-prevalence areas in order to access a greater variety and quality of care.

"... it isn't possible, it just won't happen. I cannot tell you how much of the time I'm shocked at how brilliant the services in London are, and I live, what, twenty-five miles away, and its shit. And it's much worse in other places than where I am."

Non-African Women 50 and over.

• Participants report significant challenges and barriers to the use of shared-care between GP, HIV clinics, and other secondary services.

• Participants report being and/or feeling at risk due to delays and failings in care-coordination.

• Participants with the greater comorbidity and/or years since diagnosis reported the greatest levels of concerns.

CONCLUSIONS

• Processes of care-coordination were frequently fragmented, unclear and prone to communication delays, leading to distress and confused expectations.

• Many patients perceive GPs to be lacking in HIV skills and experience, to have limited understanding of patients' experience and having poor confidentiality.

• Having access to patient records was identified as a method of increasing patient control and oversight of coordination. This was balanced by concerns around the confidentiality of digital records.

The results of this study have informed the design of a Discrete Choice Experiment (DCE), which is currently recruiting across 14 HIV clinics. The results of the DCE will be analysed in the summer of 2015.

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