Patients’ perspectives on the development of HIV services to accommodate aging: 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 aging population include polypharmacy and the risk of drug-drug interactions in the context of multiple prescribers.

AIM

1) to identify 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

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 patient’s 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) were secondary records 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 demonstrated the perceived value of GP services.

...if reforming of HIV services is going to be taking it back to the GPs, 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 over stretched as everybody knows and they don’t have time to deal with coughts and colds...

Three key themes

2. Concerns around care-coordination and communication between services

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. Strengthening 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. By GP hasn’t a clue what’s going on with my care. By MRI doctor has a more holistic view, but four NHS Trusts working on entirely 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... that’s burdening up the GP's time... It’s the burdening up the GP’s time...

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.

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.

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 contact the HIV care 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

"There’s no clue what’s going on with my HIV..." [19/10/10]

"The doctors in the HIV clinic are more holistic and have a much clearer idea of what’s going on..." [10/01/10]

Variations by degree of comorbidity and/or years since diagnosis

Significant differences 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 levels of comorbidity tended to be more dissatisfied with services and had greater reliance on specialist HIV clinics.

"...your consultants are often different to a person walking into a clinic maybe 28 years old, recently diagnosed..." and they do try to explain to to that some of the junior doctors..." [19/10/10]

"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 28 years old, recently diagnosed..." and they do try to explain to to that some of the junior doctors..." [19/10/10]

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 greatest comorbidity and/or years since diagnosis reported the greatest levels of concerns.

Varyations by region / degree of HIV prevalence

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

"...if you go to the GP it’s the same..." [07/06/09]

"I went to the clinic, as a walk-in and they said wait until you go to the GP and they refer you to the hospital..." [07/06/09]