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

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Abstract

Objectives: To identify aspects of healthcare that are most valued by people with HIV; and to describe their concerns and preferences for the future delivery of services for non-HIV related illness amongst people living with HIV (PLWHIV).

Methods: Twelve focus groups of people receiving HIV care were conducted in community settings in South-East England. Groups were quota sampled based on age, sex, sexual orientation, and ethnicity. Data were analysed using Framework Analysis.

Results: Among the 74 respondents (61% male) a preference for maintaining all care within specialist HIV clinics was commonplace, but was highest among participants with more extensive histories of HIV and comorbidities. Participants valued care-coordination, inter-service communication, and timely updates to medical notes. There were high levels of concern around HIV skills in general practices and the capacity of general practitioners (GP) to manage patient confidentiality or deal appropriately with the emotional and social changes of living with HIV.

Implications: Participants valued, and had an overall preference for, the specialist knowledge and skills of HIV services, suggesting that non-HIV-specialist services will need to build their appeal if they are to have a greater future role in the care of people with HIV. Particular concerns that should be addressed include: patient confidence in the HIV knowledge and skills of non-specialist service providers; clear processes for prescribing and referrals; improved levels of care-coordination and communication between services; increased patient confidence in the capacity of primary care to maintain confidentiality and to appreciate the stigma associated with HIV.

Key words: HIV, service use, patient preferences, qualitative.

INTRODUCTION

With increasingly effective antiretroviral therapy (ART), people living with HIV (PLWHIV) can now expect a near normal life expectancy^{1,2}. The number of older people (>50 years) with HIV rises each year. Recent estimates report that in the region of 30% of PLWHIV in the UK were 50 years or older³By 2028 this figure is likely to rise to more than 50%⁴ This cohort increasingly presents to services with multiple age-related comorbidities⁵. Multimorbidity is associated with polypharmacy and increased risk of drug-drug interactions among people taking ART^{1 5-12}.

The need for specialist care and robust confidentiality has contributed to a usual model of care in the UK in which all healthcare needs of HIV patients are managed within specialist HIV clinics. In order to manage comorbidities that could be successfully managed within primary care an integrated model of care used in other long-term conditions in the National Health Service (NHS) could be applied to HIV care¹³. National recommendations from both the Department of Health¹⁴, and from within the British HIV Association¹⁵ have prompted these changes without consideration of patients' preferences.

Systematic reviews of shared-care (between HIV specialist services and health services) have focussed on service perspectives and lacked views from service users. The most recent review identified concerns regarding sharing of care between specialist HIV clinics and non-specialist care including: expertise of health care providers, relationships between patient and healthcare provider, quick and efficient access to care, and appointment length. However, the review revealed a limited amount of research into patients' preferences for delivery of healthcare¹⁶. Recent fieldwork reported by the King's Fund has highlighted that although in general there is strong commitment to involving people in HIV services locally, almost all of the examples given were about how individual services operated, rather than how the various services combined to shape people's overall experience of living with HIV¹⁷. Therefore, aims of this study were to explore PLWHIV preferences for health care services outside of their HIV specialist services and to determine which aspects of care are valued.

METHODS

Design

This study used a qualitative methodology in the form of focus groups. The interactions within focus groups promotes the articulation of open responses, and enables detailed exploration of insights, beliefs and experiences through participant interaction, unlike other forms of qualitative research such as semi-structured interviews¹⁸. Ethical approval was granted by South Yorkshire Ethics Committee (13/YH/0256).

Participants and settings

Twelve focus groups were conducted in Brighton and London, UK, between November 2013 and February 2014. In order to seek a range of opinions we targeted distinct groups using quota sampling to reflect the main groups of PLWHIV in the UK. Groups were based on gender, sexual orientation (Men who have Sex with Men [MSM] / Heterosexuals), and African/non-African ethnicity, and each of these groups were run separately with people aged <50 years, and those \geq 50 years (Table1). The sampling strategy was employed with separate groups to acknowledge the role that stigmatization plays across gender, age and cultural background¹⁹. By running homogenous groups in regards to these particular demographic characteristics we were hoping to encourage open and honest discussions. All participants were aged \geq 16 years, diagnosed with HIV, and currently receiving HIV care. A lower age limit of 16 years was deemed appropriate since this is the lower threshold for adult HIV services. Participants were identified through advertisements and emails sent to HIV community groups, and word of mouth; two participants were recruited through HIV clinics. Under-subscribed groups with <3 participants were repeated.

Procedure

Individuals were invited to attend focus groups at community venues across South-East England and London (Terrence Higgins Trust South, Positively UK, Sussex Beacon, HIV i-base). Focus groups lasted ~90 minutes and had two moderators, one of whom was experienced in focus group facilitation and one of whom was a lay researcher with HIV. Both moderators were also diverse in terms of

gender, sexual orientation, ethnicity and experiences of using HIV services which may have supported discussions. The key facilitator directed the majority of the discussion and encouraged interaction and exploration of all issues. The co-facilitator ensured time was kept, all participants contributed and all areas of interest were covered. The co-facilitator organised the recording equipment and went through the written consent procedures. Participants were informed that there were no right or wrong answers and that their opinion was being asked for. A topic guide allowed free discussion within pre-defined topics^{18 20}. The topic guide included broad questions about experiences of healthcare and specific questions about non-HIV specialist services. Consent was received at the time of the focus group after establishing group rules. Discussions were digitally recorded and transcribed verbatim. Travel costs and a 'thank you' of £20 were offered to participants.

Analysis

Data were analysed using a Framework Analysis approach^{21 22}. This was chosen over more inductive methods, such as grounded theory, because there was both a need to explore inductively the original accounts of the respondents whilst also achieving the pre-set objective of exploring the seven hypothetical or pilot service innovations. Framework Analysis is a matrix-based approach to qualitative analysis, which uses verbatim transcripts. This technique involves identifying recurring and important themes based on a combination of a-priori issues introduced by the moderator, emergent themes, and recurring attitudes or experiences. These key themes provided main subject areas in the framework analysis and it is at this stage that comparison between coders is conducted to ensure the findings are valid. Two coders independently interpreted the data and classified supporting quotes into themes and categories. Repeated analysis produced further sub-themes and detail. Quotes from the groups were cross-coded to the themes and sub-themes, generating a detailed referencing of the discussions. Data were managed using paper and pen method rather than using management software. Further validity of the findings was ensured by discussion of any discrepancies in interpretation or classification of supporting quotes into themes generated by the two coders (AP and VC) by a third researcher (CL a psychologist with qualitative expertise).

RESULTS

Seventy four participants took part in 12 focus groups. Focus group and socio-demographic characteristics are summarised in Tables 1 and 2. Data saturation was achieved within the groups however recruitment continued to ensure quota sampling was accomplished and a diversity of people were included.

Duration of diagnosis and patients' degree of comorbidity influenced experience and perceptions of services to a greater extent than age. Those with multiple comorbidities tended to have greater reliance on and preference for specialist HIV clinics:

“...a certain group like ourselves [...] who have been diagnosed for a long time, our health issues are completely different to a person walking into a clinic maybe 26 years old, recently diagnosed [...] I think the doctors have to understand that some patients are not as well as others...”[Group 5. MSM; 50 and over]

Most participants had valued relationships with HIV clinical staff. However this relationship featured most heavily in the accounts of participants who had been diagnosed with HIV for longer or those who had experienced more comorbidities. This reliance on a familiar HIV clinic is therefore greatest among those with an increased clinical need to share care with other departments.

The HIV knowledge, skills and confidence of the health care practitioner

Participants expressed a clear preference for receiving care in specialist HIV clinics, where they had developed relationships with the staff who were trusted for their clinical skills. Staff from other hospital and primary care services were frequently considered to lack knowledge, skills and understanding of HIV. Examples of excellent GP care were cited in the groups but these usually related to GPs with a specific interest in HIV. Many participants perceived that non-specialist services lacked skills, knowledge and/or confidence to treat HIV patients. Those diagnosed for a longer time

and participants with more comorbidities also perceived that GPs had limited knowledge of the impact of HIV on other conditions:

“It’s like the on-going scientific evidence and research that’s going on around the causes of comorbidities and whether they’re linked to treatments and stuff like that - I don’t even think that is on the radar of a lot of GPs. My experience has been that they get quite anxious around anything to do with HIV...” [Group 8. Non-African Women; under 50]

Participants were often unclear about which service to present to with symptoms and preferred approaching HIV services where HCPs had greater confidence in HIV-related issues being swiftly addressed. Participants in every group reported GPs referring patients back to specialist HIV clinics:

“...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 and they don’t have time to be dealing with coughs and colds”. [Group 5. MSM; 50 and over]

Participants felt that the resulting ‘ping-ponging’ between GPs and HIV clinics was probably due to the lack of confidence by the GP to prescribe in the context of ART:

“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 I think you go back to your consultant”. [Group 12. African Women; 50 and over]

An ‘on it’ response to symptoms

HIV clinicians were perceived to be more decisive and proactive than GPs in responding to symptoms of HIV or comorbidity. The contrast between the ‘on it’ approach of HIV clinicians and the ‘wait and see’ approach of GPs was attributed to a lack of awareness among GPs of the urgency and potential severity of routine conditions in patients with a diagnosis of HIV:

“I could never get an emergency appointment [at the GP]... I’d been on antibiotics for two weeks. I could feel my chest infection getting worse and my health was really bad. I happened to have to go to my HIV clinic to pick up my meds and they said - hang on a minute, you what? And when I told them, bang - straight into hospital!” [Group 10. MSM; under 50]

There was also a perception that HIV clinics could provide faster referrals to other services:

“I ended up having to go back and forwards to neurologists and it would take the GP absolutely months and months to even get a response, but my HIV consultant spoke to him ... and literally within days it would be sorted. They seem to have a sense of urgency that the GP’s don’t have.” [Group 4. MSM; under 50]

This was understood as an indication of specialist clinics staff having a greater awareness of the vulnerabilities of HIV infection and treatment side-effects, and the risks of emerging comorbidities.

The three C’s: Care-coordination, communication and confidentiality

Participants reported that receiving care from a number of secondary departments or even across different hospital Trusts delayed communication:

“At one stage I had four NHS Trusts looking into different bits. My GP hasn’t got a clue what’s going on with my care. My HIV doctor has got a more holistic view of what I am doing 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.” [Group 10. MSM; under 50]

Participants expressed high levels of concern about communicated information being inaccurate, delayed or lost, and particularly expressed vulnerability to unreliable administration:

“They’re supposed to communicate with my GP which they didn’t do. I asked them several times to do that and my GP is saying ‘I can’t prescribe you this, I don’t know what medication you’re on, why aren’t they writing to me?’” [Group 10. MSM; under 50]

Some participants reported that the co-ordination of their care across different services was managed by their HIV clinic. This was more frequent among those with greater comorbidities. Others were managed by GPs and some participants were not able to identify any care coordination. There was limited understanding about what care-coordination patients could expect or who had responsibility for coordination. In many cases participants had developed strategies for assisting, or taking on, elements of their own care-coordination.

“...we’re still in that place where the patient has to push. The systems are not really there for you to be able to trust that everything is going to happen and be okay. As far as your HIV is concerned you can trust that it will be, but as soon as you start getting other stuff coming along, you’re back into having to be more proactive.” [Group 9. Non-African/non-MSM men; 50 and over]

Strategies adopted by participants to take control of their own care included restricting care to one hospital; collating copies of letters and test results; changing HIV clinics and GPs; and making formal complaints. Several participants advocated the use of centralised, digital medical records as a solution to communication problems. However, while some participants recognised that their confidential records in the HIV clinic were held separately from their general hospital records, this was not understood by all participants:

I thought this was what the big computer that they scrapped was supposed to do, everybody was supposed to see everything about everybody, but I’m really not sure how it works between them because I know the GPs, all my letters, everything’s computerised, and I know in my clinic everything is computerised, but I don’t think the two computer’s talk to each other...” [Group 9. Non-African/non-MSM men; 50 and over]

The potential effect of electronic records on patient confidentiality generated conflicting views about the benefits in improved communication between healthcare providers, set against perceived confidentiality risks:

“The government is pushing for everybody sharing data. It’s a worrying thing, personally [...] computerised data. As I said, it’s sometimes good for your medical team to be communicating, but along the way, in the process, confidentiality might be broken.” [Group 11. African men; over and under 50]

Although confidentiality concerns appeared in every group, they were particularly evident in heterosexual African groups, where participants had frequently not disclosed their HIV status to children and family members and where instances of disclosure had occurred inappropriately:

“...it depends, if they do know, how are they going to handle the information? That’s the scary bit. Because in my case it was said [disclosure in GP practice] right in front of everybody, even my relatives ... They hadn’t known for 14 years but all of a sudden, boom!” [Group 11. African men; over and under 50]

The social and emotional experience of HIV

Participants particularly valued working in partnership with HIV clinicians and being treated holistically. Some participants perceived that other secondary care departments and GPs lacked understanding of the social and emotional experience of HIV, and identified a need for training in this aspect of care:

“My consultant, he’s not going to ask you about health issues, he’s going to ask you about how are you coping at home, how is your social life, are you going to any of the support services, etc. So it’s not only about the illness and meds. It’s about a holistic point of view and for me that’s what I look for; what I expect from someone who is looking after my care.” [Group 10. MSM; under 50]

The degree of GPs' involvement in patients' lives contrasted sharply with that of HIV specialists, who were seen to be more compassionate and appreciative of the social and emotional context to having HIV.

DISCUSSION

This study builds on existing work, identifying aspects of care that are valued by people with HIV and their preferences for service development²³⁻³². HIV clinics have historically provided comprehensive care coordination and referral, but an ageing population, experiencing more co-morbidities, and emerging changes in the administrative commissioning of services from secondary to primary care in England have led to an increase in care management and prescribing by non-HIV specialists. Against this backdrop there was a clear preference across all groups for care to be retained within specialist HIV clinics. This preference was particularly evident among participants with a more extensive history of HIV and/or comorbidities.

Specific concerns about shared care in three areas were reported by our participants: levels of HIV knowledge, skills and confidence of staff outside of specialist services; care coordination and communication between services; appreciation of the social/emotional experience of living with a stigmatised condition. Recent systematic reviews have found shared care models to be favourable amongst patients from the perspective of services in England and developing nations, but acknowledged there were significant barriers for patients and limited evidence on the best models of shared care. A recent UK paper identified three broad categories of shared care with varying degrees of GP involvement, and highlighted the value of HIV training for non-specialists, good inter-service communication and strong clinical leadership in primary care^{17 23-28 30 32 33}.

Many participants in this study experienced '*ping-ponging*' between GP and HIV services leading to confusion about who was responsible for their care, as well as doubts about the capacity of GPs to effectively manage care. The ageing profile of people with HIV and the consequent pressure to share care has fragmented responsibilities and increased stress on inter-service communication without

concurrent improvements in coordination. A recent study of GPs perspectives on shared care found they lacked sufficient time, knowledge, experience and training to feel comfortable managing HIV-related illness and were often uncertain how to differentiate other illnesses from HIV-related illness. Needs were identified for more HIV training, better communication between GPs and HIV clinicians, and the study advocated the involvement of GPs with a special interest in HIV in the care of HIV patients²⁵. Fieldwork with PLWHIV elsewhere has indicated that patients are sceptical that the development towards shared care with GPs is being driven by cost cutting rather than by patient's views¹⁷. This perspective would need to be managed alongside the perspective that the health needs of PLWHIV are also evolving as people live longer.

Patients with HIV have typically established strong emotional and pragmatic relationships with staff in HIV clinics, who have historically met a wide range of patient needs including referral and care-coordination, as well as reassurance, in a non-stigmatising environment. In line with other patient focused studies^{24,26}, we found preferences for high standards of holistic care provided in specialist HIV clinics, and high levels of concern about the capacity of non HIV specialists to appreciate the social and emotional experience of people with HIV. Our findings support recommendations from other studies for additional skills-development for non-HIV specialist staff, including administrative staff such as receptionists^{23,25}.

Although most participants saw the benefit of information-sharing between healthcare departments, some worried how this might impact on confidentiality. Participants trusted that their HIV status was secure within HIV clinics, but many were concerned about their confidentiality in other secondary care departments and GPs. These concerns frequently focussed on non-clinical staff such as receptionists having access to their HIV status, sharing of medical information with employers or financial services, and a lack of appreciation of HIV stigma. These concerns were particularly evident among heterosexuals concerned about disclosure to families and communities. The sharing of PLWHIVs medical records is complex because although the clinical importance and implications to communication and prescribing decisions are clear, some people are distinctly against it³⁴.

Strengths and weaknesses of the study

This study included a large, diverse sample of HIV-positive patients from high and low-prevalence areas. However, it was limited to South-East England, which may limit the generalisability of findings. Additionally, convenience sampling was used, with the majority of participants recruited from HIV community organisations which may have impacted on the views of the people taking part. All participants were registered with HIV specialist services which may also have impacted on the views of people taking part. However, this is reflective of the population in the UK where nearly all of people with an HIV-positive diagnosis are registered with an HIV specialist service³.

Conclusions

Patients have strong preferences for maintaining care within trusted specialist services, and the many emerging models of shared-care have frequently failed to maintain patient confidence in the coordination of care. Any changes or new strategies implemented to ensure continuity of care for PLWHIV must be evidence based and take into account patient preferences for services. Acceptable shared-care must accommodate patients' views on: continuity of care; clear processes for prescribing; speedy referral with reliable care-coordination; and services that appreciate the importance of HIV stigma and confidentiality. Future research could explore the potential of technologies to support inter-service communication, referral, care-coordination and confidentiality within non-specialist HIV services for PLWHIV.

Table 1 Composition of each focus group

Focus group number*	Participants	n	Age: mean (range) in years	Years since diagnosis: mean (range) in years	Sex
1 & 3 & 10	MSM under 50	12	39 (19-53)	10 (1-27)	Male
2	MSM 50 and over	7	54 (50-64)	16 (3-20)	Male
4	African Women under 50	6	42 (+1 aged 55) (34-36)	6 (2-15)	Female
5	MSM 50 and over	10	56 (+1 aged 49) (52-62)	17 (5-30)	Male
6 & 12	African Women 50 and over	14	55 (50-71)	7 (7-25)	Female
7	Non-African Women 50 and over	5	60 (52-67)	19 (6-27)	Female
8	Non-African Women under 50	4	44 (40-47)	15 (6-24)	Female
9	Non-African/non-MSM Men 50 and over	5	60 (54-85)	11 (4-19)	Male
11	African Men over & under 50	11	52 (40-61)	16 (11-25)	Male

MSM = men who have sex with men

*Under-subscribed groups (Groups 1 & 6) were repeated (Groups 3, 10 & 12) to achieve target quota sampling.

Table 2 Socio-demographic characteristics of 74 participants.

	N	(%)
Male	45	(61 %)
Ethnicity¹		
White British	30	(41 %)
White other	4	(6 %)
African	30	(41 %)
Other Black	5	(7 %)
Mixed race	2	(3 %)
Sexuality²		
Heterosexual	38	(51 %)
Bisexual	4	(6 %)
Gay male	30	(41 %)
Age:		
<50	24	(32 %)
≥50	49	(66 %)
Employment status³		
Full-time Employed	23	(31 %)
Part-time Employed	6	(8 %)
Student	5	(7 %)
Unemployed	23	(31 %)
Retired/Disabled	15	(20 %)
Highest educational qualification⁴:		
No qualifications	3	(4 %)
GCSE/O Level	19	(26 %)
A level/NVQ/Diploma	29	(39 %)
Graduate degree	19	(26 %)
Post-graduate	2	(3 %)

¹ Other categories were provided on the proforma but not endorsed. Some data missing.

² Missing data.

³ Missing data.

⁴ Missing data.

(Percentages may not total 100 due to missing data and/or rounding)

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Contributors

MF, CL and AM had the idea for the study.

MF was the Principal Investigator*.

VC, NP, CL, EN, AM, and MF contributed to the study design.

MF, CL, NP, VC, EN and AP devised the qualitative part of the study.

AP and MS conducted the focus groups.

AP and VC analysed the transcripts, with input from MS.

AP and CL wrote the first draft of the paper and both contributed to revised versions.

All authors contributed to revisions of the manuscript.

*Note: the principal investigator MF has since died.

Competing interests

None

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