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“You are still a human being, you still have needs, you still have wants”: a qualitative exploration of patients’ experiences and views of HIV support

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ABSTRACT

Background

The importance of patient involvement in service redesign is gaining increasing recognition, particularly for chronic conditions. This study explored the experience, views and needs of people living with HIV to identify areas for improvement and service development.

Methods

Face-to-face, semi-structured interviews were conducted with people living with HIV being treated in two clinics in Grampian, Scotland. The topic guide was developed, based on a proposed care pathway, which emphasised support systems. Thematic analysis was undertaken.

Results

Fourteen people living with HIV participated, with time since diagnosis ranging from <1 years to >15 years. Most were male, white British and were men who had sex with men. Interviewees highlighted the need for different types of support throughout different stages of the HIV journey, including timely provision of information, post-diagnosis follow-up support, peer support, family support, and support regarding employment, benefits and housing. Many interviewees expressed a preference for support to be provided by people with knowledge or experience of HIV but had mixed feelings towards group support. Interviewees reported concerns with confidentiality and potential stigmatisation.

Conclusions

Support services should be tailored to reflect changing needs throughout the HIV journey with particular emphasis on maximising confidentiality whilst minimising stigma.

INTRODUCTION

HIV affects 35.3 million people globally.¹ Antiretroviral therapy (ART) has transformed HIV into a chronic condition requiring long-term management and care; consequently the prevalence of HIV has increased and there are now more people living with HIV (PLWH) in developed countries than ever before.² One of the challenges of HIV care is keeping patients engaged in care; estimates derived from US and European data suggest that at any time approximately 50% of HIV patients are not engaged in HIV care.³

HIV care and support “extends beyond medicines and formal health-care systems and requires adoption of new strategies that take into account the comprehensive and different needs of people living with HIV”.⁴ Recent guidelines state that HIV programmes should provide person-centred care that is focused and organised around needs, preferences and expectations of PLWH and offer acceptable and appropriate clinical and non-clinical services in a timely manner.⁵

Qualitative data from the US indicates that good communication from service providers is crucial for engaging patients with ART.⁶ Previous research demonstrated the clinical importance of patient satisfaction with HIV care provider and social support: a meta-analysis of 207 studies investigating predictors and correlates of adherence to ART found that patient satisfaction and trust with their HIV care provider and social support were strongly associated with adherence.⁷ A systematic review of patient-reported factors found that a negative view/lack of trust in the provider, social isolation and negative social support were barriers to ART adherence in developed countries.⁸ Support groups have been identified as a primary forum through which social support is provided to PLWH.⁴ While the importance of person-centred care and support for PLWH is increasingly recognised at the global level, there is limited research into the specific types of support preferred by PLWH.

In Grampian, Scotland, there were approximately 296 diagnosed PLWH as of June 2012 with 263 attending clinical services.¹⁰ As part of a service redesign, new care pathways had been proposed by the NHS board. This study aimed to bring the patient’s voice to the proposed care pathways by exploring the lived experience, views and needs of PLWH to identify areas for potential improvement.

METHODS

Study design

Qualitative study comprising semi-structured interviews. A qualitative design was chosen to allow for an in-depth exploration of participants’ experiences of care and support.

Participant selection

PLWH were recruited through the two services in Grampian which provide clinical care for adult PLWH: the Infection Unit (INFU) and Genitourinary Medicine (GUM) clinic. Study information was distributed by clinical or administrative staff to all patients attending for routine clinical HIV care during the three-month recruitment period. Individuals interested in participating provided contact details and indicated their preferred method of interview (i.e. face-to-face, telephone or focus-group). Information was returned to the research team using a reply-paid envelope. Participants were contacted (telephone or email) to arrange a time and place for interview.

Setting

Interviews were conducted in 2012. Face-to-face interviews took place at participants' clinics or on university premises. One telephone interview was conducted.

Data collection

The interview guide was structured around local care pathway proposals. It was developed with input from the NHS Grampian HIV Working Group which comprised Public Health professionals and a Consultant in Infectious Diseases. Views were sought on: experience of diagnosis; prevention; new models of care, i.e. involvement of general practitioners (GPs), health advisors (HAs), pharmacists, other clinical specialities, third sector organisations; information sources; and patient involvement. A selection of questions from the topic guide is in Table 1. The topic guide was reviewed by a doctor with clinical experience in HIV but not associated with the study. The first two interviews were considered to be the pilot phase after which interviews were reviewed for the content of the topic guide and length of interview. These two interviews were included within the sample. No changes were considered necessary.

Interviews were conducted by a Research Assistant (NF) trained in qualitative methods. Interviews were semi-structured and supplementary questions and prompts were used when necessary.

Interviews were audio-recorded with written consent.

[Table 1]

Data management and analysis

Interviews were transcribed by a research secretary then checked for accuracy. All authors coded two transcripts independently to develop a coding framework. These transcripts represented comprehensive and diverse experiences of HIV care. Subthemes were specifically kept non-directional to ensure that interviewees' positive and negative remarks were easily accommodated within the analysis. Additional subthemes were added as and when they occurred. The remaining transcripts were coded by one researcher and personally identifiable information was removed to

protect anonymity. Thematic analysis was used and the data were managed using QSR NVivo 9. Ethical approval was obtained from the NHS North of Scotland Research Ethics Committee (12/NS/0054).

RESULTS

Of the 21 individuals who provided contact details, 14 were interviewed (Table 2). Six could not be contacted and one failed to attend the interview. The mean interview duration was 62 minutes. Participants were aged from 38-58 years. The majority of interviewees were tested for HIV after becoming unwell or after their partner had been diagnosed with HIV. Antenatal screening, donating blood, occupational requirements and being advised of a former partner's HIV-status were also reasons for being tested. Two did not specify their reasons for testing. Interviewees described their support needs at various points of their HIV journey (Figure 1).

[Table 2]

[Figure 1]

Support at the time of diagnosis

Interviewees were asked about their experience of being tested and diagnosed. Several interviewees spoke about pre-test counselling. Some had not received pre-test counselling but believed it would have been beneficial. The importance of receiving information regarding what would happen following a positive or a negative test result was highlighted by those who had expressed a desire for pre-test counselling:

“Nothing was explained as to what happens after you have the test, and you've got your results, so later on that day, when I went back, and they told me it was a positive result, my biggest question was what the hell happens next, because I had absolutely no knowledge of what happened after that, what it meant.” (male, diagnosed >15 years previously)

Regarding receiving their diagnosis, several interviewees felt their experience had been worse than necessary. Many who felt this way had been tested in settings other than an HIV clinic or outside the UK:

“It was quite horrific because of the doctor that tested me, [...] unfortunately [the] GP was not a very nice person, and was very anti-feminine. When we went in, he didn't speak to me, he just spoke to my [partner]. Then he looked at me and said 'what are you here for?', knowing full well, because he'd told my [partner]. Eventually, I said 'I guess I'm here because the results were positive', and he just said 'yes', never looked up from his forms,

so I just walked out, so I was kind of in limbo for a little while.” (female, diagnosed >15 years previously)

Two interviewees, diagnosed within the UK over ten years previously, reported that they had experienced considerable delays in being able to see a consultant after diagnosis, thereby leaving them without any information for some time:

“I didn’t see anybody for about eight months, so it was quite a worrying time [...] I was more or less told to go home and not think about it, which is very difficult.” (male, diagnosed >15 years previously)

Some interviewees felt that their experience of receiving the diagnosis had been acceptable:

“It was alright actually, because I’d already thought about what would happen if I did have it and how I would cope and how I would tell my family, how they would cope, things like that, and it went all smoothly.” (male, diagnosed >15 years previously)

Support following diagnosis

The support received following diagnosis varied considerably. Some interviewees were very happy with the level of support they had received. One individual reported having a ‘buddy’ which had been beneficial. Clinic health advisors and nurses were central in providing support:

“They were fantastic, [...] they gave me information, they let me vent if I needed to talk, you know, kind of shout at somebody, let some feelings out. I’d sit and cry, I could shout, I could do anything, and they were there to listen, and they didn’t judge you, they didn’t bother what your background was, or what had happened to you, if you needed it, they were there.” (female, diagnosed 1-5 years previously)

In contrast, other interviewees felt that they had insufficient support. Some reported receiving a single visit from a health or social care professional after diagnosis:

“The only support that I had, I think I’d one visit from a social worker, and that was it, end of story, just sort of left to get on with it, which was a bit scary at the time.” (male, diagnosed 6-9 years previously)

Several interviewees felt they had needed time to absorb the “shock” of diagnosis. The timeliness of support and the need for follow-up support was highlighted by these interviewees:

“There was some health advisor came to my house, I must have been out of hospital for two or three days, but I was still getting over the shock of this, [...] whatever she was saying, I couldn’t have taken it in, [...] they’ve got to give you time, fair enough come in

then, but I think there should have been a follow-up.” (male, diagnosed 1-5 years previously)

While a few interviewees felt they did not require additional support initially and were content without it, the need for emotional support and having someone to talk to was evident in the majority of interviews:

“Sometimes just talking, I just feel if I could talk to somebody, get something off my chest, it would maybe help a bit.” (male, diagnosed 1-5 years previously)

“In retrospect it would have been good to know a bit more about how to deal with the emotional side of it.” (male, diagnosed 10-14 years previously)

Regarding who should provide this type of support, interviewees often suggested health advisors or nurses who had experience in dealing with PLWH. Two interviewees specified that someone detached from the medical team or the clinic was preferable. Local organisations, social workers and psychologists were also mentioned. Some felt that being able to speak with someone who had been through the experience themselves would have been reassuring:

“I think if you’d been able to speak to somebody that had gone through a similar situation, or had someone that was HIV positive and they’d come through it and still alive and physically well, might have put your mind at rest a bit more, [...] I was [age] at the time, I was convinced that I’d be dead [within two years].” (male, diagnosed 6-9 years previously)

The desire for this additional support to be provided somewhere other than the clinic was expressed by two interviewees, one of whom had not received this type of support and another who had.

Support from clinic staff

Interviewees were not explicitly asked for their views regarding their consultant and other staff at their clinic. However, this emerged when discussing other topics. Clinical staff were central to all interviewees’ experiences and the majority were very satisfied with the care provided:

“Best of the doctors here, marvellous, they are all fantastic here, it’s like coming to visit your family when you come here, which is good, because you don’t put off coming.” (female, diagnosed >15 years previously)

The attitudes of various types of staff were noted:

“The people that run it, [name] who does the co-ordinator, the cleaners are lovely, nurses are lovely, the doctors are great.” (female, diagnosed 1-5 years previously)

Most were extremely satisfied with the care received from their consultant but a few felt that there were areas for improvement:

“I don’t know if the doctor down here would react if I said I’m struggling to cope with this, [...] it’s just the way he is, I’m not saying that he does anything wrong, because he doesn’t, [...] there’s no ‘How you doing?’ involved, ‘How you coping with?’, there’s no chat outside of what I’m there for, which is to give me the results from my last visit, ask how I’m feeling, and I kid you not, within three or maybe five minutes, I’m in, then I’m out, done, dusted, finished.” (male, diagnosed 1-5 years previously)

Similar concerns were highlighted by two other interviewees and led to one of them having their care transferred.

Current support needs

Current support needs varied greatly. Some interviewees felt they did not need any additional support, either because they were beyond a stage when they felt it was needed or because they led full and busy lives. As previously noted, some interviewees said they would benefit from having someone to talk to with experience or knowledge of HIV.

Others suggested: an employment helpline; support with legal issues including employment and information disclosure; advice on benefits and housing; emotional support and information for family members including parents and children; a ‘buddy’ system for newly diagnosed individuals; and a support group for older PLWH.

Other support needs identified were around employment and benefit rights because some interviewees were unsure of their entitlement:

“If sometimes you could access financial help, now and then when you needed it, that would be good, because you can’t get benefits, you can’t get nothing really, unless you have small kids [...], and if idiots would learn to know that you are not dying with HIV, you are not dead, you are still a human being, you still have needs, you still have wants, you still have everything, you still have a life and it’s a life that you can live, and people shouldn’t be stigmatising, you shouldn’t be stigmatised because you are HIV positive.” (female, diagnosed >15 years previously)

This interviewee also alluded to the wider issues of employment and the difficulties in having a career due to perceived restriction in gaining employment. Two interviewees were worried about employment and how much information to disclose to employers.

“One thing I considered was actually an employment helpline thing, where you call anonymously and you can say well what would happen if I did this, and get them to go and find out anonymously.” (male, diagnosed 10-14 years previously)

A couple of interviewees were in poor health; in these cases, the need for help with benefits and housing was more pressing:

“If I’d had someone to help me with [benefits] and the housing, because I’ve to phone the housing myself, and I need to get re-housed, but honestly I just feel that it’s a big ordeal to do all this.” (male, diagnosed 10-14 years previously)

Support for partners and family members was raised. Several interviewees had children covering a range of ages who knew of their parent’s status. There were also children who had HIV themselves who had additional emotional support needs at certain stages in their lives as they grew up and started to think of the implications of their HIV status. For slightly younger children who may not have HIV, there was concern that they needed support at the stage when they started to think about the consequences of their parents’ HIV status:

“She’s aware that we all take medication. She knows it’s HIV, does she understand that? No way does she understand that, and even if I sat her down and explained, it wouldn’t equate to understanding the appreciation of what it was, of how little difference it makes to our lives, it changes everything, but nothing, you know what I mean? Just someone for her, she has nothing wrong with her, but she has everything wrong around her, so support for that.” (male, diagnosed 10-14 years previously)

The parents of interviewees were sometimes perceived as needing help in coming to terms with their child’s HIV status. Some parents might be older, and from a generation that finds open discussions challenging, therefore a one-to-one session was suggested:

“It could have been a social-worker type person, someone coming in from outside, or a GP that she knew. To go to a group, you know, family or families of people with HIV, [is] not up her street at all.” (male, diagnosed 10-14 years previously)

A few female interviewees expressed a desire for a group aimed at older people. This was in response to previously attending groups that were dominated by younger men, many of whom were gay. There was a desire for peer-support from those with similar circumstances:

“I wouldn’t mind it being mixed [gender] at all, but the idea of having youngsters in about? No.” (female, diagnosed >15 years previously)

Some interviewees expressed a dislike of groups partly due to fear of being identified but also due to a lack of desire or ability to open up to others:

“I knew people from [previous group] who discussed my status outwith the group and that to me was unforgivable, [...] when you get phone calls from people, who have heard on the grapevine, it is soul destroying.” (male, diagnosed >15 years previously)

Hearing about negative experiences of others was also considered to be depressing by some interviewees.

DISCUSSION

Main findings of this study

The findings highlight the desire for different types of support for PLWH at different stages of their HIV journey. Services should be tailored to reflect different needs throughout the HIV journey with a particular emphasis on maximising confidentiality while minimising stigma.

What is already known on this topic

In 2015, 88,769 PLWH were accessing HIV care in the UK; 69% were male and 31% were female.¹¹ Of the 6,095 individuals diagnosed in 2015, 82% were aged 15-49 years and 17% were aged 50 years and over. The probable route of transmission was men who have sex with men in 54% of cases, heterosexual intercourse in 39% and injecting drug use in 3%.¹¹ This demonstrates the range of potential service users that HIV services need to be able to support.

Previous research demonstrated that patient satisfaction and trust with their HIV care provider and social support were strongly associated with adherence.⁷ Similarly, a negative view/lack of trust in the provider, social isolation and negative social support were barriers to ART adherence in developed countries.⁸

What this study adds

The current study indicates that PLWH had additional support needs that were not always met and illustrated the desire for support both soon after acceptance of diagnosis and long after diagnosis. The findings demonstrate that care and support need to be tailored to individuals. Whilst support groups have previously been identified as the primary way to provide support to PLWH, the current study indicates that these may need to be formed around specific groups of PLWH. Furthermore, this option was not acceptable or desirable to some participants and therefore alternative methods of providing social support are required.

There was generally a preference for support by people who had knowledge or experience of HIV; therefore, sufficient knowledge or training is likely to be required for those who provide support services for HIV. However, preferences were mixed regarding whether this support should be provided in the clinic environment or within the community. These findings have implications for where support services are located. It is likely that close links between clinical services and support services will be needed.

Limitations of this study

Participants came from a limited geographical area; however, a range of demographics were represented in terms of age, sex, ethnicity, sexual orientation and length of diagnosis.¹⁰ Data saturation was not achieved due to the limited time scale available for this research.¹²

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Table 1. Selection of questions contained in the topic guide

Testing and diagnosis

- Experience of testing?
- Improvements regarding testing?
- Experience of receiving diagnosis?
- Improvements regarding receiving diagnosis?

Treatment and care

- Seek views on clinic
- Experience of clinic? (e.g. confidentiality, space, staff)
- Is your GP involved in your HIV care?
- Experiences regarding GP and HIV care?

New models of care

- How involved would you like the Health Advisors to be involved in your HIV care?
- How would you feel about seeing a Health Advisor instead of a doctor when your condition is stable?

Voluntary or other organisations

- Awareness of any other support services for people with HIV available in Grampian?
- Experience of use?
- Improvements?
- Any needs that are not being met?

Table 2. Participant demographics (n=14)

	n
Gender	
Male	9
Sexual orientation	
Men who have sex with men	6
Ethnic group	
White British	11
Black, African or Caribbean	2
Other	1
Time since diagnosis (years)	
<1	1
1-5	3
6-9	1
10-14	4
>15	5
Currently using HIV medication	
Yes	13

Figure 1: Identified support needs at different stages of participants' HIV journey