

## Introduction

It is recommended for every person living with a diagnosis of HIV to have access to psychological support appropriate to meet their needs (BPS, BHIVA & MEDFASH, 2011). Community psychological support is available in some areas but is not available consistently across the UK.

HIV prevalence is concentrated in more vulnerable and stigmatised sectors of the population, contributing to increased health inequalities. People living with HIV face psychological challenges including stigma, managing their health condition, and medication side-effects (NAT, 2010). The HIV population have increased incidence of mental health, and depression is a risk factor for HIV infection (Whetten et al, 2008).

Research also suggests that people living with HIV who are more distressed have poorer health outcomes (Johnson et al, 2003; Cook et al, 2002).

In the local area, the community service offers a range of support, including a drop-in centre and peer support groups.

It is recommended that the design and evaluation of services should involve people living with HIV, in a way that enables "means of gaining an insight into the way patients perceive their health and the impact that treatments or adjustments to lifestyle have on their quality of life" (BPS et al, 2011, p.39).



## Aims, Design and Method

The current study aimed to explore the impact on health and wellbeing of community-based support for people living locally with HIV.

The research was positioned within a social constructionist stance, and used a qualitative approach to explore individuals' experience and the perceived impact of accessing one community service, whilst acknowledging a wider social context.

One focus group took place in each of two locations using semi-structured interviews, with a total of 9 participants. Participants were largely, although not exclusively, of black African origin. Thematic analysis was used to code data and interpret the main themes and sub-themes.

## Selected References

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- Cook, J. A., Cohen, M. H., Burke, J., Grey, D., Anastos, K., Kirstein, L., ... & Young, M. (2002). Effects of depressive symptoms and mental health quality of life on use of highly active antiretroviral therapy among HIV-seropositive women. *JAIDS Journal of Acquired Immune Deficiency Syndromes*, 30(4), 401-409.

# “We can still live a positive life”: The experience and impact of community support for people living with HIV

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## Results

Three overarching themes emerged through interpretation of the data:

“They know how weak they are now, from the time they were, to now, and it’s for them to say about improving things by stepping in the way they used to, because we can’t change them can we?”

“It can take up to 6 months for some people to really attend the group... because people understand the stigma.”

“When you’re feeling down, you know that there’s something there that you can call for help.”

1. *Value of the Service:* Participants discussed the support offered, how this has changed over time, and access to the service.

“(The service) is not getting the support to be supporting other people.”

“Some people don’t realise that we still have a future. We can still go to school, we can still live a positive life just like anyone else. It’s not the end of the world.”

“I had a husband, I had a family here, but he just deserted me.”

“That’s what our health is all about: you’re not supposed to feel lonely, you’re supposed to have somebody to comfort you any time. Because we always feel low, you understand?”

“The service is important, that’s why I’m saying that it builds you, it gives you confidence.”

3. *Value of Community Inclusion:* Participants explain the positive effect on their health and wellbeing of feeling part of a community, often likened to a new family.

“What we share... we wouldn’t share with our biological brothers.”

“When I was diagnosed I thought the whole world had collapsed, I had nobody to talk to.”

2. *Emotional Challenge of HIV:* Participants described how living with HIV isolates and impacts well-being.

“You get stressed when you’re lonely, it’s stressful when there’s nobody there to stand by you, you get stressful over a lot, a lot of things, that’s why I’m saying that this can change for what you are.”

“After discovering these groups, my whole life, my condition has gone uphill. I was down there.”

## Conclusion

The emergent themes and component sub-themes comprise of and illustrate the following:

### *Quality and value of the local community service*

There were many valued aspects of the service, but a strong theme was change over time. It was perceived that the service had gone downhill, and it was speculated that austerity had led to funding cuts. Some participants felt that if communication was more open about this then the impact could be reduced.

### *Impact of living with a diagnosis of HIV*

It was clear how devastating the impact of HIV diagnosis had been not just to health but also emotional well-being, isolation and sense of self. Attention was drawn to the diversity of experiences and coping responses. Due to perceptions of and actual experiences of stigma, participants described losing family, friends, and having to reach a level of acceptance on their own in order to reach out to community support.

### *Value of community inclusion and belonging*

Participants also described how the support of the community was important to them and their relationship to living life with HIV. Valued aspects included having a place to share, express and make sense of their situation, and led to connection, a sense of belonging, increased confidence, and feeling like a valid and valued human being.

### *Critical reflections and discussion*

Whilst participants described it being useful to “disclose” within the group, there were participants who had not moved on to disclose their status outside of the immediate community group.

Previous research emphasises the need for support to be culturally appropriate, particularly given the social context of stigma and marginalisation (Brondani et al, 2012). This research suggests that there are still many barriers to accessing community support following diagnosis.

The literature on HIV management in the UK and US is dominated by individualist health psychology models or medical perspectives. The current research highlights the significance of community context, echoing theories that call for ‘community mobilisation’, or increased collective agency to managing health and social pressures (Campbell & Cornish, 2010).

### *Where next?*

The results currently presented are preliminary as brief interviews will shortly be conducted with staff members, in order to add further context to the data.

In conclusion, there is a clear benefit to mental and physical health for people living with HIV having access to community support, however, broader social issues are apparent that this model of community support appears limited in tackling.

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